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Health on the margins

How can the Seventh-day Adventist church, with its emphasis on health, authentically proclaim liberty for people with disabilities?

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Awarding institution:
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Doctorate in Theology & Ministry
Assignment Cover Sheet

Student name: Patrick Johnson

Course Title: Research Based Thesis

Title of assignment: Health on the margins: How can the Seventh-day Adventist church, with its emphasis on health, authentically proclaim liberty for people with disabilities?

Word count: 56,935

Date: 4th December 2018

Abstract

The subject of disability has only begun to receive attention in the Seventh-day Adventist church in recent years. This thesis sets out to explore how such a health-conscious denomination can create local church environments that are welcoming for people with disabilities. The assumption behind this question is that an emphasis on health will result in a more medically minded membership which in turn can produce (often unconsciously) oppressive attitudes towards people with disabilities.

The body of the research uses Richard Osmer's four core tasks of practical theology as a method for exploring the research question. As this is one of the first projects to study disability in the Seventh-day Adventist church it was important to begin by hearing the voice of members with disabilities. Consequently, the study is based on empirical research conducted with twelve individuals with physical disabilities and their experiences of church. The emerging themes from the research, which range from incidents of discrimination on the negative side to experiences of belonging on the positive side, are then first explored through the social scientific lenses of sociology and psychology. The theological motifs of the image of God, sin, eschatology and the priestly prohibitions in the Old Testament book of Leviticus are then examined from a theological perspective to illustrate that a more relational hermeneutic can be disability affirming.

The final practical theological task culminates with the suggestion of a seven-step process of change adapted from John Kotter's organisational change theory. This is suggested as the practical strategy for the Special Needs coordinator to follow in order to bring about the kind of change that will lead a local Seventh-day Adventist congregation to become a place of liberation for people with disabilities.

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Acknowledgements

There are several people who have contributed to me being able to complete this task, whose input I would like to acknowledge. First of all, I would like to express my thanks to my friend Gifford Rhamie who recognised in me a growing hunger to do further study and who encouraged me to start on this journey of deeper study. I am indebted to my supervisor, Paul Joyce, for his enthusiastic optimism that fuelled the momentum to bring this project to its conclusion. His positivity was particularly invaluable during the times when I did not think I was able to make any more progress. In the same way I am deeply thankful to Val Bernard-Allen for her patient and personal supervisory help.

I have really valued those who have shown an interest in this project such as Mike Pearson and Cynthia Benz, who each gave significant and meaningful insights into different aspects of this project. My thanks also go to each of the participants who were willing to be interviewed, and to Jacquelyn Johnson and Jonquil Hole, who both freely offered to proofread this piece of work.

I was very fortunate to have a quiet place to study in the Roy Graham Library at Newbold College. Consequently, I am very grateful to the librarians, Per Lisle and Linda Baildam, who willingly made their resources available to me.

Finally, I would like to thank my friends and family for their support throughout this long course of study. I especially want to name my wife, Kari, for her patient support, and my son Espen, who was not only the catalyst for this thesis but also a sounding board who helped me to keep my feet on the ground.

Chapter 1 - Introduction

“I don’t want to go with you to visit other churches anymore.” This was the unexpected conclusion that my then teenage son, Espen, announced after one such visit. As a pastor in the Seventh-day Adventist church for more than fifteen years, I had, up to this point, always tried to take my family with me on speaking appointments that involved my travelling to churches outside of my pastoral district. Being in England gave them a special opportunity to experience different church cultures, which I thought was a good form of education, so this declaration came as quite a shock.

On further probing Espen described his dislike of the oftentimes bizarre attention that he would receive as a wheelchair user. Then he concluded, “People don’t see me, they only see my wheelchair.” That statement hit me like a bolt of lightning. I was so used to having him with me that I had not thought so much about how he experienced church. This prompted me to want to explore this some more. What makes us view people with disabilities with such special attention? No doubt there are social and psychological theories to explain this, but what about in the church? Should a different attitude be expected of Christians?

More specifically, how would this apply to my own faith community in particular, the Seventh-day Adventist church? At our world General Conference session in 2016, a new position was created for Special Needs. This shows our church’s commitment to being more conscious of the needs of this group. As this ministry develops, what pitfalls should we be aware of? Is our view of disability particularly coloured by our inherent emphasis on health? Is this an advantage or disadvantage when it comes to how we treat people with disabilities?

Many other Christian denominations have developed from merely providing services to advocating for full participation in church life for people with disabilities.¹ This shows that the adoption of a social understanding of disability has been a somewhat intuitive

¹ Albert A. Herzog, ‘Disability Advocacy in American Mainline Protestantism’, *Journal of Religion, Disability & Health*, 10.1–2 (2006), 75–92 <https://doi.org/10.1300/J095v10n01_06>.

progression for them. But for Seventh-day Adventists their emphasis on health adds a layer of complexity that may hamper a similar progression.

1. Adventism and Health

Tillotson et al point out that the acceptance of people with disabilities depends on “the discourse present within the Christian faith community.”² One of the prevailing discourses within the Seventh-day Adventist church is that of health, so it is no surprise that the church is known perhaps foremost for the benefits its members derive from its emphasis on health.³ Adventists attribute this somewhat unique insight to the writings of one of its pioneers, Ellen White (1827-1915). What could arguably be called Ellen White’s foremost summary purpose statement on health reform⁴ shows that she believed it was theocentric, based on a wholistic anthropology and meant to promote the wellbeing of all.⁵ Briefly probing the significance of the latter two beliefs will illustrate why the Seventh-day Adventist concept of health can be problematic in relation to people with disabilities.

1.1 Adventist health and wholeness

In mentioning the development of ‘body and mind and soul’ Ellen White illustrates the type of wholistic anthropological thinking that is typical within Adventism. In her chapter entitled ‘Wholeness’, Ginger Hanks-Harwood demonstrates how the idea of wholeness has become quite significant in the Adventist church.⁶ ‘Wholeness, as it was developed in Adventist theology, represented the nexus of conditionalism, transcendentalism, and the

² Nicole Tillotson and others, ‘Faith Matters: From a Disability Lens’, *Journal of Disability & Religion*, 21.3 (2017), 319–37 (p. 328) <<https://doi.org/10.1080/23312521.2017.1348924>>.

³ Dan Buettner, *The Blue Zones: 9 Lessons for Living Longer from the People Who’ve Lived the Longest* (Washington D.C.: National Geographic Partners, LLC, 2012), pp. 121–65.

⁴ Angel Manuel Rodriguez, ‘The Theological and Practical Significance of Health Reform in the Writings of Ellen G. White’, *Journal of the Adventist Theological Society*, 25.2 (2014), 132–57.

⁵ ‘In teaching health principles, keep before the mind the great object of reform—that its purpose is to secure the highest development of body and mind and soul. Show that the laws of nature, being the laws of God, are designed for our good; that obedience to them promotes happiness in this life, and aids in the preparation for the life to come.’ Ellen Gould Harmon White, *The Ministry of Healing* (Nampa, Idaho: Pacific Press, 2003), p. 146.

⁶ *Remnant and Republic: Adventist Themes for Personal and Social Ethics*, ed. by Charles William Teel (Loma Linda, CA: Loma Linda University, 1995), pp. 127–44.

health reform movement.⁷ She explains that conditionalism was the belief that life is only found in Christ and immortality is only for 'the regenerate' because we are free moral agents. It was a reaction to the doctrine of eternal hell for sinners that was a result of the teaching on predestination. Transcendentalism was the idea that inner reform is necessary before social reform. It includes the themes of harmonious living with nature and the importance of an inner search for meaning. Health reform focused on techniques for natural healing as opposed to the then current practices of drugging and bleeding patients, and was based on understanding the natural processes of the body to aid in self-healing.

Hanks-Harwood summarises the significance of this in the following way:

In sum, the doctrine of wholeness has had a significant impact on the Adventist church. Its presence can be demonstrated in our theology, anthropology, ecclesiology, and ethics. It has provided the church with a central part of its identity and sense of mission. It would be hard to envision the history of the church without the doctrine of wholeness, since this theme is woven into almost every recurrent theme and doctrine of the church.⁸

The main ethic coming from wholeness was that 'the medium was indeed the message'.⁹ In other words, the gospel was to be embodied by those who were proclaiming it. Ellen White seemed to underline this in order to stress the importance of health reform. However, the potential disadvantage of this is that one could infer that a certain norm or standard of health is expected to accompany the proclamation of the gospel. This could leave the subconscious impression that the healthier a person is, the more they are seen as representative of the message that God wants to give to the world. In other words, wholeness can lead to a form of health essentialism.

Such an attitude could potentially become problematic for people with disabilities for it raises the question of whether they are seen as enjoying the same level of health as everyone else. Are people with disabilities viewed as being in some way below the normal

⁷ Teel, p. 128.

⁸ Teel, p. 133.

⁹ Teel, p. 131. This is based of course on the popularly quoted phrase of the media theorist, Marshall McLuhan, 'the medium is the message.'

standard of health, however that may be defined, and thus seen as less useful in the mission of the church? How does Adventism's innate drive towards wholeness react to the presence of a person with a chronic incurable condition? The empirical research of this study was designed as an attempt to illuminate whether the experience of people with disabilities in the Seventh-day Adventist church shows them as equal or in some way inferior to their more able-bodied counterparts in the church.

1.2 Adventist health and individual responsibility

Continuing to Ellen White's belief in health reform as promoting the wellbeing of all, this is attested to by her extensive contributions to health education in the denomination. The first Seventh-day Adventist periodical devoted to health education was called *The Health Reformer*. Ellen White's article in the first edition, published in 1866, clearly underlines the responsibility of the individual to be informed of and to practise health reform principles.

Many seem to think they have a right to treat their own bodies as they please; but they forget that their bodies are not their own. Their Creator who formed them, has claims upon them that they cannot rightly throw off. Every needless transgression of the laws which God has established in our being, is virtually a violation of the law of God, and is as great a sin in the sight of Heaven as to break the ten commandments. Ignorance upon this important subject, is sin; the light is now beaming upon us, and we are without excuse if we do not cherish the light, and become intelligent in regard to these things, which it is our highest earthly interest to understand.¹⁰

One of the challenges with the writings of Ellen White is that of applying the ideas of a spiritual leader from the Victorian age to modern day situations. The danger Seventh-day Adventists constantly face is in using her writings to limit rather than encourage serious reflection.¹¹ Is her emphasis on individual responsibility for health a limiting factor? The following excerpt from a recent article in the *Journal of the Adventist Theological Society* illustrates that the emphasis she placed on individual responsibility for health is still evident in Adventist writing today.

¹⁰ Ellen G. White, 'Duty to Know Ourselves', *The Health Reformer*, 1866, 2–3 (p. 4).

¹¹ Michael Pearson, *Millennial Dreams and Moral Dilemmas: Seventh-Day Adventism and Contemporary Ethics* (Cambridge: Cambridge University Press, 2008), p. 47.

The restoration of the moral image of God in the race cannot take place apart from a transformation in thinking. The apostle Paul leaves us little room to maneuver around the question of how we might bring glory to God in the words: “whether you eat or drink, or whatever you do, do all to the glory of God” (1 Cor 10:31). This means responders to God’s appeal develop advanced ideas about healthful living... God’s instruction on the value of human life relates also to preserving health and avoiding self-harm. The work of health reform enables clear thinking and assists in the reconstruction of God’s image in followers (sanctification). Indeed we can hinder the advancement of heaven’s work and misrepresent God to others by our disregard for the principles of healthful living. The apostle Paul, in typical fashion, is quite blunt asserting that it is the duty of Christians to present their bodies a “living sacrifice” to God (Rom 12:1).¹²

Naturally, health is a personal commodity and the onus to live according to recommended principles of health lies with the individual. At the same time, whenever health reform is sought in a community of people there is also the risk of generating a kind of elitism where it is possible to single out groups who do not seem to comply with the expected norm.¹³ This is another way in which the Adventist focus on health can potentially be disadvantageous for people with disabilities.

Emphasising individual responsibility for health is very reminiscent of the medical approach to disability, which sees disability as residing with the individual who needs assistance from the medical profession to fix their problem. Similarly, if disability is viewed solely as a problem of the individual member, then those members can easily be seen as needing help from others. Could this be said to give rise to attitudes of pity, offers of unsolicited intercessory prayer, comments implying lack of faith on the part of people with disabilities bringing lack of healing, and a general lack of empathy for a person with a chronic condition? In other words, could it be said that patronising attitudes are a natural

¹² Warren A. Shipton, ‘Ellen White, Health, and the Third Angel’s Message: Part 1 - Improving Health through Reducing Transmissible Diseases’, *Journal of the Adventist Theological Society*, 28.1 (2017), 61–91 (pp. 61–62).

¹³ For example, in current debates about the ‘sugar tax’ and the various manifestations of ‘fat taxes’, such levies are seen by some as an unfair targeting of people who struggle with obesity.

consequence of Seventh-day Adventism's underlying individual health emphasis?

Furthermore, as pointed out by Stahl,

Our current Christian communities must become less concerned with individual health and instead recover a Christian conception of communal health. This is not to say that individual disease or disability should be overlooked; rather, caring for those with disability or disease must be understood as a political and inherently eschatological act. Our current understanding of "health," which is a wholly individualized commodity, has obscured Christ's vision of God's Kingdom.¹⁴

Thus, the overarching argument of this thesis is that a wholistic anthropology, when combined with an emphasis on individual responsibility for health, will lead to a form of health essentialism that discriminates against people with disabilities. Were the Seventh-day Adventist church to expand its health emphasis beyond individual duty towards communal responsibility, the cultural shift needed to create an inclusive environment for people with disabilities would become possible.

This reasoning has led me to the following research question: How can the Seventh-day Adventist church, with its emphasis on health, authentically proclaim liberty for people with disabilities?

In order to explore this, other questions will be used:

- What is the essence of the experiences of those with a physical disability vis-à-vis the church and its theology?
- How might the theology of the image of God influence Adventism's attitude towards disability?
- Can the Adventist health message have a foundation other than the medical model?

¹⁴ Devan Joy Stahl, 'A Christian Ontology of Genetic Disease and Disorder', *Journal of Disability & Religion*, 19.2 (2015), 119–45 (p. 140) <<https://doi.org/10.1080/23312521.2015.1020186>>.

2. Chapters Outline

To explore the research questions, this dissertation can be viewed as comprising two main parts. Chapters 2-4 will lay the groundwork, whereas chapters 5-8 will provide the body of the argument.

Chapter 2 will give an overview of some of the literature on disability in order to provide a brief grounding in the subject. Christian research into disability is reviewed to show how authors have addressed attitudinal barriers and theological ignorance in order to meet the overarching challenge of narrowmindedness in the church. The resulting overview will illustrate the lack of research conducted from a wholistic anthropology which signifies a space for Adventist research.

Chapter 3 explores three main positions from which disability has been defined: medical, social and experiential. The advantages and disadvantages of each perspective are considered before arriving at a suggested definition that seeks to incorporate the strengths of each position.

Chapter 4 outlines the epistemological considerations for the choice of methodology. Locating the study in the field of practical theology, the chapter explains the four main points of the pastoral cycle that are applied to questions pertaining to practical theological enquiry. Osmer's four core tasks of practical theology are then elaborated as a chosen framework for working through the next four chapters of the thesis.

Chapter 5 seeks to answer the question of what is happening in the Seventh-day Adventist church in terms of disability experiences and provides the data that is illustrative of a wholistic anthropology. It does this by firstly looking at the considerations that went into creating the empirical research, namely: worldview, research design and the research process. Then secondly, it elaborates on the empirical findings, showing how the participants describe their experiences as being depicted on a continuum from negative to positive experiences.

Chapter 6, in seeking to understand why the particular themes of the previous chapter were found, will explore three different explanations. Sociological clarifications will focus

primarily on various ways in which disability can be said to offer a challenge to society. Psychological explanations will feature the three emotions of fear, pity and disgust. Doctrinal accounts will suggest that the way in which the themes of the image of God, sin and heaven are understood, can contribute to discriminatory attitudes towards disability.

Chapter 7 addresses the normative question of what ought to be happening. It does this by examining theological themes, ethical reasoning and an example of good practice, and suggests communality as a consistent key throughout. The theological themes will include the image of God, sin, eschatology and the priestly prohibitions. Ethical reasoning will suggest that Adventists need to move more towards virtue ethics in dealing with issues pertaining to disability. Finally, three principles will be taken from the L'Arche community, which serves as an example of good practice.

Chapter 8 proposes a change process for local churches based on two main components. The first considers the form of leadership that is necessary and suggests a transformational type of leadership. The second component examines John Kotter's eight stage process for leading change and suggests this as a framework for how the Special Needs coordinator can lead a similar process in a local church setting.

Chapter 9 concludes by showing how the themes that were identified from the data have been addressed in chapters 6-8, thereby answering the main research question. It brings the thesis to a close by suggesting areas for further investigation.

Chapter 2 – Literature Review

The aim of this chapter is to give an overview of the literature and to situate this study. It will be divided into two parts. The first part will give a brief historical setting and the second part will look at the Christian response to disability. This overview will then show a gap in the literature that this study will attempt to fill.

1. History

The history of disability in Britain since the Industrial Revolution can be divided into two parts.¹⁵ First is what can be called a period of ‘institutional living’, which describes how people with disabilities ended up living in institutions such as workhouses, hospitals, asylums and schools. These establishments were particularly undergirded by eugenic ideas of the hereditary nature of impairment.¹⁶ Second is what can be called the period of ‘community living’, which encompasses experiences of people with disabilities in finding work, gaining access to financial aid and community care. This phase illustrates how people with disabilities were often the poorest in society and thus the soil was fertile for the anger that fuelled the movement for change.

Disability literature started to emerge during the community living phase when people with disabilities began to voice their dissatisfaction of the way they had been treated by society and the limited opportunities that were given them.¹⁷ Thus, for example, *Stigma*¹⁸ gives the

¹⁵ Anne Borsay, *Disability and Social Policy in Britain since 1750: A History of Exclusion* (Basingstoke: Palgrave Macmillan, 2005).

¹⁶ Borsay, p. 199. See also Susan M. Schweik, *The Ugly Laws: Disability in Public* (New York: NYU Press, 2009) which traces the history of these laws from the late nineteenth to early twentieth centuries in the USA. Organisations like the Charity Organisation Society, whose aim was to tackle idleness, fraud and begging, attempted to organise charitable giving rather than merely leaving people to rely on random acts of charity. Their rhetoric was of curing disability. Schweik notes that the desire to rid the streets of ‘undesirables’ begs the question of where they were supposed to go, hence the development of institutions such as poorhouses and special medicalised homes and hospitals.

¹⁷ *Routledge Handbook of Disability Studies*, ed. by Nick Watson, Alan Roulstone, and Carol Thomas (New York: Routledge, 2012), p. 93.

¹⁸ *Stigma: The Experience of Disability*, ed. by Paul Hunt (London: Geoffrey Chapman, 1966).

personal accounts of twelve people with disabilities, *Pride Against Prejudice*¹⁹ gives the personal experience of disability from a feminist perspective by using the stories of eight women, and *Disability Politics*²⁰ includes the personal accounts of twenty-nine people who were central to the disabled people's movement. These three examples are typical of liberation movement texts which attempt to write history intentionally from the perspective of people with disabilities.

1.1 Legislative history

The disability rights movement that arose with the emerging literature on disability has been successful in ensuring that physical access to buildings for people with disabilities became a legal requirement. International legislation came via the World Health Organization's first attempt in 1980 at a universal definition of disability.²¹ Then in response to criticisms of its reliance on medical definitions, making assumptions of normality, implying that impairment was the cause of disability and handicap, and making people with impairment dependent on professional experts,²² a new definition was reissued in 1993 which included a greater clarification of the role of social factors in disability. The more current World Health Organization framework for defining disability is the *International Classification of Functioning, Disability and Health* 2001. It endeavours to shift the focus from disability as a separate category to focus on a person's level of health and how they function in society, and it attempts to combine the medical and social models of disability into a 'biopsychosocial model'.²³

The World Health Organisation also seeks to promote the awareness and implementation of the *United Nations Convention on the Rights of Persons with Disabilities*, which was adopted in 2006 and came into force 3 May 2008. This is a comprehensive outline of the political,

¹⁹ Jenny Morris, *Pride against Prejudice: Transforming Attitudes to Disability* (London: Womens Pr Ltd, 1991).

²⁰ Jane Campbell and Michael Oliver, *Disability Politics: Understanding Our Past, Changing Our Future* (London: Routledge, 1996).

²¹ *International Classification of Impairments, Disabilities, and Handicaps: A Manual of Classification Relating to the Consequences of Disease*, ed. by World Health Organization (Geneva: World Health Organization, 1980).

²² Watson, Roulstone, and Thomas, p. 16.

²³ See <http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf> p. 9. (accessed 22 December 2016).

social and economic rights of people with disabilities. It 'reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms.'²⁴

In Britain, the most significant piece of legislation was the Disability Discrimination Act.²⁵ It became law in 1995 subsequent to the government's recognition that disability discrimination was a real problem. This has now been replaced by the Equality Act 2010²⁶ which, among other things, outlines the duty of organisations like churches to make reasonable adjustments to ensure that people with disabilities are able to receive the same services, as far as this is possible, as someone who is not disabled.

1.2 Academic history

Alongside this growing legislation was the development of studies into disability. The first international journal exclusively addressing disability issues came in 1986 and was named *Disability, Handicap and Society* later renamed *Disability & Society* in 1993. The first editorial set out its aim which was 'to provide a forum where various issues and questions on disability and handicap can be highlighted and discussed.'²⁷ With regard to Disability Studies more specifically, the Society for Disability Studies, founded in 1982 and adopting its current name in 1986,²⁸ published the first journal in this field known as the *Disability Studies Quarterly*.

The ensuing development of disability studies has seen the discourse around disabilities advanced in different directions. The first language in which disability issues were expressed was that of 'the social model of disability' which was first formulated by Michael Oliver.²⁹ This way of theorising disability as a socially constructed form of oppression, counteracted the prevailing medical model's view of disability being an individual defect and

²⁴ See <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> (accessed 22 December 2016).

²⁵ See <http://www.legislation.gov.uk/ukpga/1995/50/contents> (accessed 22 December 2016).

²⁶ See <https://www.gov.uk/guidance/equality-act-2010-guidance> (accessed 22 December 2016).

²⁷ 'Editorial', *Disability, Handicap & Society*, 1.1 (1986), 3–4 (p. 3)
<<https://doi.org/10.1080/02674648666780011>>.

²⁸ See <http://disstudies.org/index.php/about-sds/mission-and-history/> (accessed 22 December 2016).

²⁹ Michael Oliver, *Social Work with Disabled People*, Practical Social Work (London: Macmillan, 1983), p. 23.

gave rise to terms such as disablism³⁰ and ableism.³¹ Postmodernism has now repositioned the debate to engage in more intersectional discourses that include race, feminism, gender and sexuality, class and religion.³²

2. Christianity and Disability

Although Disability Legislation has ensured that public buildings and institutions, which of course include religious spaces, now have physical access for people with disabilities, compliance with statutory regulations may draw attention away from an important failing of the Christian church. This is because wheelchair accessible ramps in a building can symbolise that a church is disability friendly, whilst masking a lack of deep communality in the congregation in general and for people with disabilities in particular.³³ Hence the idea that 'Narrow doorways are more easily rectified than narrow mindsets.'³⁴

The scope of the Christian literature addresses both physical and mental disability across a wide spectrum. The scholarship challenges narrow mindsets in two main ways, firstly, by investigating matters affecting attitudinal barriers, and secondly, by exploring issues that relate specifically to theological understanding. Although, there are some positive testimonies contained in the discussion, it is fair to say that both treatments present Christian communities as resistant, patronising and discriminatory.

2.1 Suggestions for overcoming attitudinal barriers

The attitudes of church members towards people with disabilities present a major obstacle to inclusion. The literature suggests that attitudes can be influenced for the better when

³⁰ Paul Abberley, 'The Concept of Oppression and the Development of a Social Theory of Disability', *Disability, Handicap & Society*, 2.1 (1987), 5–19 <<https://doi.org/10.1080/02674648766780021>>.

³¹ Simi Linton, *Claiming Disability: Knowledge and Identity*, Cultural Front (New York: New York University Press, 1998).

³² See Chapter 3: Defining Disability.

³³ Wolf Wolfensberger, 'The Normative Lack of Christian Communality in Local Congregations as the Central Obstacle to a Proper Relationship with Needy Members', *Journal of Religion, Disability & Health*, 4.2–3 (2001), 111–26 <https://doi.org/10.1300/J095v04n02_08>.

³⁴ Jill Harshaw, *God beyond Words: Christian Theology and the Spiritual Experiences of People with Profound Intellectual Disabilities* (London: Jessica Kingsley Publishers, 2016), p. 34.

communities are shown how to progress from fear to friendship; however, achieving this shift is complex and contradictory.

2.1.A Addressing issues of fear

Dennis and Murdoch's investigation of attitudes among parish members towards including people with disabilities in the life of the parish identified fear as one of the major barriers to successful inclusion.³⁵ This seemed to encompass a general fear of difference as well as a specific fear for the safety of their children.³⁶

The fear of difference seems to be a major attitudinal barrier that is addressed in scholarship. For example, the writings of Jean Vanier, famously known as the founder of the international L'Arche movement,³⁷ address the topic of fear of difference by emphasising the fact of our common broken humanity,³⁸ by encouraging the need for embarking on a personal journey of inner freedom and healing that moves from 'exclusion to inclusion and from fear to trust',³⁹ and by calling for the creation of communities where people have a sense of true belonging.⁴⁰ Others attribute the fear of disability in Christian communities to a lack of understanding and the misplaced belief that the Christian path is meant to be easy.⁴¹

Rosemary Radford Reuther suggests that the fear is not so much of difference but rather of similarity. The reason why people with mental illness have been treated so poorly is not simply due to the fear of their potential to be violent (which is actually quite rare), but rather due to the unsettling realisation that 'the borders between madness and sanity are variably permeable, that there are elements of insanity in all of us, and that it is not easy to

³⁵ Rea Dennis and Trish Murdoch, 'Disability Focus Groups: A Strategy for Including People with Disability in Parishes', *Journal of Religion, Disability & Health*, 5.4 (2001), 45–59
<https://doi.org/10.1300/J095v05n04_04>.

³⁶ Dennis and Murdoch, p. 52.

³⁷ Started in 1964 when Vanier invited Raphael Simi and Philippe Seux to leave the institution they were living in to go and live with him in a small house in Trosly-Breuil, France. The community that grew out of this household became known as L'Arche or The Ark. L'Arche is now an international group of communities inspired by Vanier's example where people with and without learning disabilities live and share life together.

³⁸ Jean Vanier, *From Brokenness to Community*, The Wit Lectures (New York: Paulist Press, 1992).

³⁹ Jean Vanier, *Becoming Human* (Toronto: House of Anansi Press Inc., 2008).

⁴⁰ Jean Vanier, *Community and Growth* (New York: Paulist Press, 1989).

⁴¹ Kathryn Greene-McCreight, *Darkness Is My Only Companion: A Christian Response to Mental Illness*, Second edition (Grand Rapids, MI: Brazos Press, 2015).

be sure where one ends and the other begins.’⁴² She offers the history of how people with mental illness have been treated by the medical profession as evidence for the result of this type of fear. It is a history of using chains and other inhumane restraints, shock therapies and lobotomy. Similarly, church communities can be said to manifest their fear through body language, jokes and relational poverty.⁴³

Dennis and Murdoch’s proposed strategy for overcoming fear and promoting greater congregational inclusivity was the development of a Disability Focus Group.⁴⁴ This is basically a small group designed to promote adult learning, and to reach out to its wider environment with information and support for families with members with a disability. The evidence suggests that these types of focus groups have a positive effect not only on individuals with disabilities but also the church at large. The down side to this is that it demands a high level of personal commitment from those who are the catalysts for change. Unless the desire to create an inclusive church environment for people with disabilities is owned by the congregation at large, the enthusiasts are prone to suffer burnout.⁴⁵

2.1.B Facilitating personal friendships

Other scholarship suggests that a more effective method for promoting greater congregational inclusivity could be the adoption of some form of individual befriending. Writers focusing on issues of mental health and learning or intellectual disability⁴⁶ have particularly emphasised the importance of this. Swinton, for example, points out the need for separating people from their illness labels in order to offer a friendship that is rehumanising.⁴⁷ This would require developing friendships that are not based on the usual dynamics of reciprocity but rather on following Jesus’ model of grace to those we may not have much in common with.

⁴² Rosemary Radford Ruether and David Ruether, *Many Forms of Madness: A Family’s Struggle with Mental Illness and the Mental Health System* (Minneapolis: Augsburg Fortress, 2010), p. 105.

⁴³ John Swinton, *Resurrecting the Person: Friendship and Care of People with Mental Health Problems* (Nashville: Abingdon Press, 2000).

⁴⁴ Dennis and Murdoch, p. 53.

⁴⁵ This will be further explored in Chapter 8: The Way Forward.

⁴⁶ The term ‘learning disability’ is the preferred UK terminology, whereas ‘intellectual disability’ is the most recent term being used in current disability theology. See Harshaw, p. 14.

⁴⁷ Swinton, *Resurrecting the Person*.

This idea is further developed in Young's exploration of the desert fathers whom she posits as exemplifying a spirituality that moved beyond merely focusing on personal well-being.⁴⁸ She makes the case that being able to welcome the difference of others, such as people with disabilities, not only teaches us that we are also pilgrims and strangers on this earth,⁴⁹ but our ability to welcome God's difference will also deepen our own spirituality.⁵⁰ This also echoes the conclusion of her personal journey in understanding the profound learning disability of her son, Arthur.⁵¹ Arriving at the place where she was able to view Arthur as a gift rather than a problem was the result of understanding that our dignity, rather than being something inherent, is actually something we give to each other. Thus, we all, abled and disabled alike, are givers and receivers.

This giving of friendship is deepened in Reinders' exploration of profound intellectual disability.⁵² He reasons that humanness is found in the fact that we are created in God's love; in other words, it is based on something extrinsic to us. Hence, he argues that the practical outworking of this is to first receive God's friendship in order to extend Christian friendship to others, particularly those with profound mental disabilities.⁵³

These authors make a clear case for Christian communities to be able to build friendships based on the gracious acceptance of difference and gifting one another with dignity. However, this is not a straightforward endeavour. In the personal recounting of her failing mental health, Welten recognises that people suffering with mental illness can be difficult to be around. This is an important acknowledgement because the quality of friendship that is being called for goes beyond the religious community's usual response of patronising benevolence.⁵⁴ Nevertheless, she reminds the Christian community that they are looking for

⁴⁸ Frances Margaret Young, *Brokenness and Blessing: Towards a Biblical Spirituality* (London: Darton Longman & Todd, 2007).

⁴⁹ Young, *Brokenness and Blessing*, p. 92.

⁵⁰ Young, *Brokenness and Blessing*, p. 100.

⁵¹ Frances Margaret Young, *Arthur's Call: A Journey of Faith in the Face of Severe Learning Disability* (London: SPCK, 2014).

⁵² Hans S Reinders, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics* (Grand Rapids, MI: Eerdmans, 2008).

⁵³ Reinders, pp. 24–27.

⁵⁴ Nancy L. Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability* (Nashville, TN: Abingdon Press, 1994), p. 74.

a place to belong, a place where they are befriended as people rather than viewed from the labels their illness has given them.⁵⁵

Kathryn Greene-McCreight suggests that in order to facilitate friendship the general fear of mental illness can be eased by making a distinction between the brain being sick but the soul not being sick.⁵⁶ She also underlines how vitally important the Christian community is for people suffering with mental illness because it helps them lean on the faith of the community when they do not have faith themselves. When everything seems dark and hopeless the community helps the person suffering with mental illness to remember what God has done in the past and will do in the future. Taking the significance of the community even further, Radford Ruether goes so far as to hint that in the case in schizophrenia, having an accepting social setting together with the frameworks that can interpret them could make hearing voices acceptable in some situations.⁵⁷ This may be overstating the case as far as the Christian community is concerned, nevertheless it does underline the pivotal role that social bonding can play in the lives of people with disabilities.

Some research has shown that a befrienders programme has been found to result in the increased social inclusion of people with intellectual disabilities.⁵⁸ However, as the authors themselves acknowledge, this research was only done from the point of view of the befrienders. Further studies need to be conducted which focus on people with disabilities themselves to ascertain how they perceive the effectiveness of such programmes on their sense of belonging.⁵⁹

In contrast to this, Brennan and Rutledge discovered more positive attitudes among church members when they studied able-bodied attitudes towards physically impaired clergy.⁶⁰ The research participants were found to be supportive of having clergy with a disability,

⁵⁵ Christine Welten, 'Wanting to Belong', *Journal of Disability & Religion*, 18.3 (2014), 286–90 <<https://doi.org/10.1080/23312521.2014.928990>>.

⁵⁶ Greene-McCreight.

⁵⁷ Ruether and Ruether, p. 54.

⁵⁸ Angela Novak Amado and others, 'BeFriends: Impact of a Social Ministry Program on Relationships for Individuals with Intellectual/Developmental Disabilities (I/DD)', *Journal of Religion, Disability & Health*, 17.1 (2013), 1–26 <<https://doi.org/10.1080/15228967.2013.752926>>.

⁵⁹ Amado and others, p. 23.

⁶⁰ James R. Brennan and Debra Rutledge, 'Attitudes of Able-Bodied People Toward Clergy with Impairments: A Photo Elicitation', *Journal of Religion, Disability & Health*, 17.2 (2013), 77–90 <<https://doi.org/10.1080/15228967.2013.780829>>.

showing a willingness to use whatever resources were necessary in order to make adaptations. This seems to contradict some of the previous findings by indicating that church members may have more positive attitudes towards disability than may be feared. However, this study could be said to be more reflective of the privileged position and high regard that clergy have among their parishioners, rather than signifying a new trend of positive attitudes towards disability.

2.1.C Resilience and inclusion

There is some suggestion that the church's idealising of the family as an effective functioning unit also serves to contribute to a view of families with children with disabilities as failing families, and it is likely that their negative visibility prompts a sense of fear amongst other members. Studies also show that churches that manage to respond positively, do so as a direct result of parents' ability to advocate for their disabled child's inclusion. Their proactive and resilient attitude is the cause of this shift. Thus, the level of social and emotional capital that parents must display must be greater than the community's tendency to exclude.

Research focusing on the factors that parents of children with learning difficulties identify as affecting their inclusion and participation in their faith communities, found that one third of respondents had changed their place of worship because their children were not accommodated, and half of them were never asked to participate or provided with support.⁶¹ This suggests that churches still have work to do in making individualised adaptations for children with disabilities. This assertion is supported by O'Hanlon's research on the specific religious community activities and behaviours that families of children with disabilities consider supportive.⁶² Positive experiences were related to a higher frequency of participation in different activities. However, the study showed that there are still large numbers of families and children who report having negative experiences (more than 50%) even though they are regular attendees.

⁶¹ Melinda Jones Ault, Belva C. Collins, and Erik W. Carter, 'Factors Associated with Participation in Faith Communities for Individuals with Developmental Disabilities and Their Families', *Journal of Religion, Disability & Health*, 17.2 (2013), 184–211 <<https://doi.org/10.1080/15228967.2013.781777>>.

⁶² Elizabeth E. O'Hanlon, 'Religion and Disability: The Experiences of Families of Children with Special Needs', *Journal of Religion, Disability & Health*, 17.1 (2013), 42–61 <<https://doi.org/10.1080/15228967.2012.731874>>.

Studies reporting positive assimilation into a church community by families of children with disabilities has shown the importance of resilience in parents.⁶³ Resilient parents were identified as those who were willing to communicate with leaders, take on leadership or volunteer roles themselves, advocate for their children and engage in problem-solving. In other words, it was the initiative of the parents in procuring individual adaptations for their child that ensured a positive outcome. This ability to act on your own behalf or to advocate for others has also been found to be a key characteristic of resilient people who are said to live well with their disabilities.⁶⁴

Given Christianity's call to mission and community, it is ironic that the above discussion on overcoming attitudinal barriers characterises churches as resistant and unaccommodating social spaces. The suggestion that fear, whether of difference or similarity, is a major attitudinal barrier is a rather disappointing finding in communities that claim to follow Jesus who sought to bring a message of love that casts out fear. The evidence points to the need for a strong call to a new way of building friendships within Christian communities. The quality and depth of friendships with people with disabilities can therefore be said to be a yardstick by which to measure how Christlike a community is actually becoming. The highlighting of resilience leads one to question whether there are underlying theological reasons why the church appears to be so poor at adapting to needs without parents or people with disabilities themselves needing to act as catalysts.

2.2 Developing an inclusive theological understanding

The discussion surrounding theological understanding will show that there is to date no coherent theology of inclusion. It also attests to the development of new discourses that challenge the very heart of some of the core assumptions within Christianity. The various discussions, challenge some of the fundamental assumptions and demand hermeneutical reconstructions that provide a robust and sensitive theology of inclusion and equality. It is suggested in the literature that these can be achieved through challenging the assumptions

⁶³ Evin Winkelman Richardson and Zolinda Stoneman, 'The Road to Membership: The Role of Resilience in Seeking and Maintaining Membership in a Faith Community for Families of Children With Disabilities', *Journal of Disability & Religion*, 19.4 (2015), 312–39 <<https://doi.org/10.1080/23312521.2015.1093442>>.

⁶⁴ Katherine M. Clarke and Francine Cardman, 'Spiritual Resilience in People Who Live Well with Lifelong Disability', *Journal of Religion, Disability & Health*, 6.1 (2002), 23–36 <https://doi.org/10.1300/J095v06n01_03>.

of physical normality by requesting that disability becomes visible, by an analysis of medical discourses, by deconstructing stereotypical assumptions and by seeking out and reconstructing radical hermeneutics.

2.2.A Making disability visible

The Christian discourse has been accused of lacking an experiential validation of the accounts of people with disabilities. Some have observed that paradoxically it is often people with disabilities who may feel the most powerless, who have to take the initiative to remind their communities of their existence.⁶⁵ Although it is clear that people with disabilities have become more visible in society, by and large this is not the case in church communities.⁶⁶

The idea that the size of Christian communities is linked to levels of visibility and therefore inclusion, is raised by Larocque and Eigenbrood. They offer some insight into the issue of physical access and their conclusions suggest that the size of the congregation is a significant factor in determining accessibility for people with disabilities.⁶⁷ Smaller congregations, defined as having less than 500 members, were found to be less accessible than larger ones. A couple of suggested reasons for this finding were that larger congregations were more likely to have larger numbers of people with disabilities attending their services thereby putting pressure on the church administrators to make required changes. They would also have, when compared with smaller congregations, greater financial ability (due to church members giving larger and regular offerings) to make the necessary physical adjustments. Such findings highlight economic power as contributing to the impetus and justification for increasing the visibility of disabled people, thus raising suspicions surrounding the authentic value that relationships hold in Christian communities.

Brock observes that the standardisation procedures of socio-political systems make it all too easy for people with disabilities to become invisible because of the need to attend to the

⁶⁵ Roy McCloughry, *The Enabled Life: Christianity in a Disabling World* (London: SPCK, 2013).

⁶⁶ Linda L. Treloar, 'Spiritual Beliefs, Response to Disability, and the Church -Part 1', *Journal of Religion, Disability & Health*, 3.4 (2000), 5–32 <https://doi.org/10.1300/J095v03n04_02>.

⁶⁷ Michelle Larocque and Rick Eigenbrood, 'Community Access: A Survey of Congregational Accessibility for People with Disabilities', *Journal of Religion, Disability & Health*, 9.1 (2005), 55–66 <https://doi.org/10.1300/J095v09n01_04>.

masses rather than those who statistically fall on the margins of society.⁶⁸ He goes on to argue that since a theological understanding of quality of life is corporate, the Church should be better placed to ensure that people with disabilities are visible. Even though research shows that the medical profession has not been listening attentively, especially to people with disabilities,⁶⁹ by contrast, the church should be an attentive listening community because it is trained in the regular practice of listening to God through its corporate body. Since the research does not seem to corroborate such a conclusion, perhaps the problem lies in how attentively the church listens to the parts of its body that are affected by disabilities.

Another area where disability is often invisible is found in the eschatological imaginary. Belser proposes that ‘the assumption that disabled bodies and minds all desire and require healing – functions as a form of violence and a kind of imperialism.’⁷⁰ Her premise is that an imagined future that envisions the erasing of disability is an impoverished one. She argues that Old Testament references to the healing of all disabilities should be read bearing in mind a social context where deliberate disfigurement during war was practiced as an act of dominance. Hence, the future healing of blindness, for example, should be viewed as liberation from oppression and the removal of all the consequences of war, rather than the elimination of inconvenient bodily difference.

Thus, the literature suggests that making disability visible as a step in developing an inclusive theological understanding will require at least two degrees of listening. Firstly, there is the need to listen attentively enough to surpass the generalising and normalising motives of the socio-political world. Secondly, making disability visible will require listening long enough to allow disability to impact eschatological imaginations.

2.2.B Marginalising medicalised discourses

An emphasis on wholeness has a direct negative relationship with a medicalised definition of disability. This widely held but problematic view is expressed throughout the Christian

⁶⁸ Brian Brock, ‘Quality of Life and the Statistical Outlier: On Caring in an Industrialized Age’, *Journal of Disability & Religion*, 18.4 (2014), 318–39 <<https://doi.org/10.1080/23312521.2014.928989>>.

⁶⁹ Brock, pp. 322–27.

⁷⁰ Julia Watts Belser, ‘Violence, Disability, and the Politics of Healing: The Inaugural Nancy Eiesland Endowment Lecture’, *Journal of Disability & Religion*, 19.3 (2015), 177–97 (p. 178) <<https://doi.org/10.1080/23312521.2015.1061470>>.

scriptures. The scriptural emphasis on illness as an individualised experience requiring healing can create a blind spot to the productive understanding of disability as socially constructed and the disabled person as permanently different, dignified and included.

Research into the experiences of stroke survivors, for example, has shown that church communities have a tendency to view them through a medical lens, hence they reported receiving positive support during the acute rehabilitation stage but not during the long-term chronic phase of their new existence.⁷¹ This seems to illustrate that the lack of a discourse on chronic illness can result in a general expectation within the Christian community that sickness will improve within a short period of time. When faced with chronic illness the community will then tend to shift its attention elsewhere. Hence, the testimonies of people with chronic illness that reflect feelings of invisibility⁷² suggest that they do not seem to fit within a church culture that is full of activity and striving to be efficient.

Treloar's qualitative study, which aligns with an Adventist mindset because it was conducted from an evangelical Christian perspective,⁷³ investigated the spiritual experiences of 30 people affected by disability. While the participants reported that their spiritual beliefs were very important to how they cope with their disability, they also emphasised the significance of attitudinal accessibility.⁷⁴ One way of promoting a more positive attitude suggested by Treloar's research participants would be for the church to directly address disability and related issues in order to encourage a theological understanding of the meaning of disability.⁷⁵ Sadly, for some participants, the lack of theological engagement with the meaning of disability resulted in their moving away from the church and even from God.

⁷¹ Peggy J. Goetz and Marie Bloem, 'An Ethnography of Stroke Survivors in Their Church Communities', *Journal of Disability & Religion*, 19.3 (2015), 243–61 <<https://doi.org/10.1080/23312521.2015.1058210>>.

⁷² Goetz and Bloem, pp. 251–53.

⁷³ Even though there has previously been much debate within Adventist circles about whether the term 'evangelical' should be used to describe themselves, today it is generally viewed as an acceptable description. See for example, *Lutherans & Adventists in Conversation: Report and Papers Presented 1994-1998*, ed. by Gemeinschaft der Siebenten-Tags-Adventisten and Lutherischer Weltbund (Silver Spring, Md: General Conference of Seventh-day Adventists [u.a.], 2000); Stefan Hörschele, *Interchurch and Interfaith Relations: Seventh-Day Adventist Statements and Documents*, Adventistica, Bd. 10 (Frankfurt: Peter Lang, 2010).

⁷⁴ Linda L. Treloar, 'Spiritual Beliefs, Response to Disability, and the Church-Part 2', *Journal of Religion, Disability & Health*, 4.1 (2000), 5–31 <https://doi.org/10.1300/J095v04n01_02>.

⁷⁵ Treloar, 'Spiritual Beliefs, Response to Disability, and the Church-Part 2', p. 16.

2.2.C Deconstructing unhelpful assumptions

There have been some theological attempts to deconstruct old stereotypical assumptions and some of these attempts propose a radical revision of ingrained assumptions within Christian theology. This involves a theology that neutralises notions of sin by including disability into the understanding of what life is, linking notions of the Godhead more closely with narratives of disability, centralising vulnerability within narratives of the human condition, and an undermining of narratives of redemptive bodies to one that centralises a continuum of human limitations.

One of the ideas that is confronted in the literature is the overriding assumption that disability is something negative. Cox, for example, uses Jesus' declaration in Matt 18:8-9, that a person can 'enter life maimed', to argue that the life that is referred to is not so much concerned with physical wholeness but rather about following Jesus, hence physical disability should be viewed as being consistent with life not sin.⁷⁶

Eiesland argues that negative attitudes in the church towards people with disabilities are the direct result of fusing sin with disability. Due to the visible nature of physical disability, she reasons that a theology of liberation needs to 'create new images of wholeness as well as new discourses'.⁷⁷ Hence her proposal is that the symbol of Christ be changed from suffering servant to disabled God, because Christ's resurrection body remained physically impaired with the nail prints and pierced side. This is particularly portrayed in the giving and receiving of the Eucharist.

The work of Reynolds illustrates that the idea of normality is another concept that would need to be addressed if churches are to show a greater hospitality towards people with disabilities.⁷⁸ He deconstructs what he terms the 'cult of normalcy' because its idealising of youth, beauty and wealth lead to the pursuit of an idyllic life that very few can realise. His proposal is that human vulnerability is the healthiest starting point for building a more hospitable church community because it builds on humanity's mutual interdependence.

⁷⁶ Jennifer Anne Cox, 'Entering Life Maimed: The Compatibility of Disability and Life', *Journal of Disability & Religion*, 20.3 (2016), 203–12 <<https://doi.org/10.1080/23312521.2016.1204170>>.

⁷⁷ Eiesland, p. 92.

⁷⁸ Thomas E. Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality* (Grand Rapids, MI: Brazos Press, 2008).

In a similar vein, Yong challenges the reader to acknowledge that we usually have a 'normate' reading of the Bible which makes certain texts have a negative view of people with disabilities.⁷⁹ This is seen as the underlying reason for the discriminatory attitude that is so prevalent in the church. Using a number of biblical examples, he illustrates how a disability perspective could give a different understanding of the text, which could form the foundation for a more inclusive church.

The idea of a cult of normalcy resonates with the work of Tillotson as the attitude of ableism.⁸⁰ She points out that one of the consequences of ableism is the assumption that faith may be irrelevant to the wellbeing of certain people living with disabilities. Her phenomenological study was designed to explore the importance of faith and her findings indicate that faith can empower and build the resilience of people living with disability. Long's phenomenological study into embodied disability narratives among Christian church leaders in Britain, found that ableism is a pervasive force in church culture and infrastructures, particularly as it propagates images of humanity that are characterised by the ableist values of wholeness, beauty, strength and normality.⁸¹

In summary it can be said that the literature strongly implies that deconstructing negative images of disability is an important step in the development of a disability inclusive theology. However, such an endeavour is not without its difficulties. While it could be accepted that new symbols are useful, there is the danger that in using physical disability to reconceive God, as Eiesland does, that this could set up a hierarchy of disabilities, where people with profound intellectual disabilities always end up at the greatest disadvantage.⁸² In other words, it could also be argued that adopting a minority-group understanding of disability can lead to more antagonism rather than solutions in that it creates a them-and-us mentality among disabilities.

⁷⁹ Amos Yong, *The Bible, Disability, and the Church: A New Vision of the People of God* (Grand Rapids, MI: Eerdmans, 2011).

⁸⁰ Succinctly defined as 'the presumption and privileging of able-bodiedness' in Tillotson and others, p. 320.

⁸¹ Sarah Anne Long, 'Seeking the Intrinsic Quality of Life', *Journal of Disability & Religion*, 19.3 (2015), 209–27 <<https://doi.org/10.1080/23312521.2015.1061468>>.

⁸² Reinders, pp. 24–27.

The production of a them-and-us mentality is undermined by Creamer's inclusive limits model.⁸³ She proposes that the category of disability is unnatural and should be deconstructed, hence her proposal of a limits model. Her argument is that since limits are a natural part of what it means to be human, there is no need to single out certain types of limits by calling them disabilities. Embodiment theology asserts that since we are embodied beings all theological reflection is necessarily done from an embodied perspective, hence it must attend to the many different forms that our bodies take, thereby leaving room for more variety without problematising our differences.

Furthermore, conclusions from works such as those of Reynolds and Yong, which build their cases through the lens of the social model of disability, need to be nuanced. Although the social model of disability has been a necessary and positive development in the understanding of disability, more recent scholarship has critiqued it for its reliance on simple binary distinctions,⁸⁴ for inadequately addressing theological prejudice,⁸⁵ and for neglecting the significance of individual experience.⁸⁶

2.2.D An individualised approach

Claassens' exploration of the story of Job exemplifies how to gain a theological understanding of disability that sensitively views individual experience in a way that can be empowering.⁸⁷ She points out that Job was thrust into the world of disability with the accompanying stereotypical attitudes towards sin, suffering and being under God's curse. However, the speeches of God reveal a particular narrative that suggests that God's attitude is based on how he is personally related to every individual creature by virtue of the fact that he has created each one with its own peculiar existence. This in turn should inform our attitudes towards each person as possessing their own unique blend of foibles and eccentricities and worthy of unconditional dignity and respect.⁸⁸ Swinton frames this in

⁸³ Deborah Beth Creamer, *Disability and Christian Theology: Embodied Limits and Constructive Possibilities* (Oxford: Oxford University Press, 2009).

⁸⁴ Tom Shakespeare, *Disability Rights and Wrongs Revisited*, Second edition (New York: Routledge, 2014).

⁸⁵ Harshaw, p. 40.

⁸⁶ Jenny Morris.

⁸⁷ L. Juliana M. Claassens, 'Countering Stereotypes: Job, Disability, and Human Dignity', *Journal of Religion, Disability & Health*, 17.2 (2013), 169–83 <<https://doi.org/10.1080/15228967.2013.752927>>.

⁸⁸ Claassens, p. 177.

terms of thin and thick understandings.⁸⁹ ‘Thin’ understandings of people describe only the superficial and obvious, and lead to superficial forms of inclusion. ‘Thick’ descriptions, on the other hand, allow us to see the whole person and potentially lead to people actually experiencing a sense of truly belonging to a community.

The work of Hull exemplifies a more personal approach to a theological understanding of disability by describing his method of reading the Bible as a conversation. His conversation begins with feeling alienated from the Bible because of its bias towards sightedness and its negative metaphorical use of blindness. This then deepens into an acceptance of his blindness as a gift from God because it has allowed him to pass beyond light and darkness to a deeper understanding of God himself.⁹⁰ Hull’s approach helps his readers follow his personal journey of how he came to understand that blind people live in a very different world from that of sighted people.⁹¹

Hull also proposes a way of conceptualising disability other than the medical and social models. He terms this the ‘life-world model’ which is based on the phenomenological approach of Alfred Schutz and Thomas Luckmann.⁹² This is based on the social reality experienced by human beings grouped according to certain ‘provinces of meaning’, the most basic of which is the everyday life-world, which is built on a ‘stock of knowledge’ accumulated during the course of everyday life. Hull proposes that each major disability can be viewed as a life-world because the person with a disability will develop a stock of knowledge that is fundamentally different from those without that particular disability. His point is that there are many different human worlds but ‘unless the multiplicity of worlds is recognized, the one humanity simply becomes the dominant world of the normal.’⁹³ In other words, unless the uniqueness of the disabled world is acknowledged, everything in church life will be measured from the perspective of the ‘normal’ majority.

⁸⁹ Swinton, John, ‘From Inclusion to Belonging: A Practical Theology of Community, Disability and Humanness’, *Journal of Religion, Disability & Health*, 16 (2012), 172–90 <<http://dx.doi.org/10.1080/15228967.2012.676243>>

⁹⁰ John M Hull, *In the Beginning There Was Darkness: A Blind Person’s Conversations with the Bible* (London: SCM Press, 2001).

⁹¹ John Hull, *On Sight and Insight: A Journey into the World of Blindness* (London: Oneworld, 1997).

⁹² John Martin Hull, ‘Through the Many to the One: Diverse Human Worlds and the Path to Human Understanding’, *Journal of Disability & Religion*, 19.3 (2015), 198–208 <<https://doi.org/10.1080/23312521.2015.1062349>>.

⁹³ John Martin Hull, p. 207.

Vikdahl's research can be seen as providing an illustration of this dynamic. Her qualitative investigation of the idea of participation, features interviews with persons with intellectual disabilities who are members of the Church of Sweden.⁹⁴ The results showed that even though they were participating in church services, the interviewees were still being marginalised because their participation was measured in terms of normality. An example of this was a person who was baptised but had not been given any instruction as to the meaning and significance of baptism. In other words, those members of the Church of Sweden with intellectual disability were experiencing being marginalised because their participation was being interpreted and articulated in terms of normalisation by the majority rather than adapting to their individual needs.

The need for a flexible individualised approach in developing an inclusive theological understanding has challenging implications for the Adventist church. On the one hand, Vikdahl's observations are particularly pertinent because preparation for baptism is a very intellectually rigorous process in an Adventist context. How should someone with intellectual disabilities be prepared for baptism? Yet on the other hand, Hull's individualised conversation can run the danger of being a very subjective reading of the Bible. An Adventist hermeneutic would tend to ask first what the narrative meant for the original audience before making personal applications. Resolving these kinds of tensions will need to be addressed at the organisational level of the denomination as well as in the local church context.

Conclusion

This review of Christian literature on disability has illustrated how dealing with the challenge of narrow mindsets has been explored in terms of attitudinal change and theological understanding.

Attitudinal barriers such as fear, relational distance and passive reliance on the resilient initiative of people with disabilities suggest a noticeable lack of healthy values in the Church.

⁹⁴ Linda Vikdahl, 'This Is What Most People Do: Participation and Normalcy in the Church of Sweden', *Journal of Religion, Disability & Health*, 16.3 (2012), 248–61 <<https://doi.org/10.1080/15228967.2012.702412>>.

Treloar suggests that the lack of a wholistic view of people can result in a failure to minister to people with disabilities.⁹⁵ Given that research into the significance of wholeness has not yet been done, this presents a gap in the literature that Adventist research into disability could fill.

The little research that has been done on disability from a Seventh-day Adventist perspective has been connected to the area of education, where there have been repeated calls for more diversity to be represented in Adventist schools.⁹⁶ Hence, research has been done to investigate the perceptions of teachers toward the inclusion of students with disabilities in their classrooms,⁹⁷ and the effects of fully including elementary school aged pupils with learning difficulties in the Adventist classroom.⁹⁸

I believe however that research into the experience of members from the Adventist community could provide data on the effect that the idea of wholeness has on a Christian community. Hence, this research will investigate whether a wholistic approach to the individual can transcend typically ableist assumptions in order to naturally embrace people with disabilities. This will be achieved by asking members of the Seventh-day Adventist church with disabilities about how they have experienced inclusion in their church communities. The findings will then be used as a basis for proposing a way forward that will include attitudinal, theological and structural change.

Scholarship highlighting the importance of inclusive theological understanding has shown the need to make disability at least as visible in the Church as it is in wider society by directly engaging disability theologically. The lack of a theology of chronic illness, for example, has illustrated how a medicalised view of chronic illness and disability can end up marginalising people. The entrenched assumptions of normality and ableism within Christian

⁹⁵ Treloar, 'Spiritual Beliefs, Response to Disability, and the Church-Part 2', p. 20.

⁹⁶ James A. Tucker, 'Toward a Christian Understanding of Students with Disabilities', *The Journal of Adventist Education*, 58.2 (1995), 9–13; James A. Tucker, 'Pedagogical Application of the Seventh-Day Adventist Philosophy of Education', *Journal of Research on Christian Education*, 10. Special Edition (2001), 309–25.

⁹⁷ Marcel A. A. Sargeant and Donna Berkner, 'Seventh-Day Adventist Teachers' Perceptions of Inclusion Classrooms and Identification of Challenges to Their Implementation', *Journal of Research on Christian Education*, 24.3 (2015), 224–51 <<https://doi.org/10.1080/10656219.2015.1104269>>.

⁹⁸ Connie Lee Hale, 'The Inclusion of Students with Actual or Perceived Learning Disabilities in the Seventh-Day Adventist Elementary Classroom' (La Sierra University, 2009) <<http://search.proquest.com/docview/305141630?accountid=44389>>.

communities need to be actively deconstructed by showing how weakness and vulnerability have been transformed into the currency of strength in the Bible, thus allowing disability to inform biblical hermeneutics. A consequence of this is that the Church will need to find room for more individualised approaches if they are to be welcoming social spaces for people with disabilities. Applying these theological perspectives to the Seventh-day Adventist church could have an enormous impact.

Chapter 3 – Defining Disability

The aim of this chapter is to arrive at a definition of disability that can provide a suitable point of reference for a developing Seventh-day Adventist⁹⁹ disability ministry. Admittedly, such an endeavour can be charged with assuming a right to define other people's reality and accused of being reductive and universalising. As Shildrick points out, 'the dream of a common language..., of perfectly faithful naming of experience, is a totalizing and imperialist one.'¹⁰⁰ However, this exploration of definition is a matter of pragmatism. It is an attempt to influence the meanings that are often given to disability, especially bearing in mind that the ministry that will be developed in the SDA church will determine the policies and practices that will affect the lives of its members with disabilities.

In order to do this, we will focus on three main ways of viewing disability. Firstly, we will look at the advantages and disadvantages of defining disability medically. Secondly, we will consider the pros and cons of defining disability from a social point of view. Finally, we will explore more contemporary ideas of how to define disability experientially.

1. Defining Disability Medically

People with disabilities have been labelled in a variety of ways throughout history. In our day, political correctness demands that we use terms that do not offend any person or group. But with constantly evolving ideas of what is socially acceptable, it is questionable whether such an ideal will ever be attainable.

1.1 Advantages of medical categories

It is the medical profession that has the longest history of providing society with the vocabulary for describing disabilities in the form of labels and classifications. For example, my son's condition is known as Morquio's syndrome which is part of a group of conditions

⁹⁹ Hereafter abbreviated to SDA.

¹⁰⁰ Watson, Roulstone, and Thomas, p. 33.

that fall under the classification of mucopolysaccharidosis, frequently abbreviated to MPS. There are six conditions in this group and Morquio's syndrome is number four. In turn Morquio's syndrome is divided into two different strains A and B. In other words, the condition that my son suffers with is classified as MPS IV A.

It would be somewhat ungracious not to acknowledge that the ability to classify conditions has proved to be extremely useful. It means, for example, that there are now doctors who specialise in inherited metabolic diseases, and who understand the signs and symptoms and have the expertise in recommending treatment for the MPS diseases. The importance of this should not be overlooked or downplayed. People like my son who live with life-long pain welcome the assistance that medical expertise can bring. So, a definition needs to acknowledge the significance of biological factors in disability.

1.2 Disadvantages of medical definitions

However, medical classifications always start with an assumption of functional limitation or deficit that needs to be rectified. There is an underlying notion of normal functioning against which the disability is measured. There are at least three main problems with this medical model of disability.

1.2.A The problem of power

Medical definitions portray disability as something negative. It is seen as a loss of either function or ability. This results in an imbalance of power,¹⁰¹ which then is experienced as oppressive by the weaker party. The disabled person becomes a passive recipient of treatment by an all-powerful medical profession. The idea of disability oppression is explored by Charlton. He suggests that,

Oppression is a phenomenon of power in which relations between people and between groups are experienced in terms of domination and subordination, superiority and inferiority. At the centre of this phenomenon is control. Those with power control; those without power lack control.¹⁰²

¹⁰¹ Thomas E. Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality* (Grand Rapids, MI: Brazos, 2008), p. 25.

¹⁰² James I. Charlton, *Nothing about Us without Us: Disability Oppression and Empowerment*, 3. Dr (Berkeley, CA: Univ. of California Press, 2004), p. 30.

He goes on to explain that power is quite abstract and elusive but shows itself in many different dichotomous relationships such as between teacher and student, or doctor and patient.¹⁰³ The subtle way in which power manifests itself is not so much in the physical but the metaphysical, that is, by people consenting to the power structure that already exists.¹⁰⁴ Hegemony is the name given to the spiritual character of power, where it is portrayed as natural by the ruling class, and accepted as such by the oppressed. Alienation is the psychological response of the oppressed that results in 'self-pity' and 'self-annihilation'. Thus Charlton concludes that, 'Hegemony and alienation are two sides of the same phenomenon – ideological domination.'¹⁰⁵

It is the assumption of loss that often leads the Christian community to view people with disabilities from a starting point of paternalistic pity. This results in people with disabilities being on the receiving end of acts of charity from their more able-bodied benefactors. Even though charitable assistance may be well meant, it inadvertently situates the person with disabilities as a social burden.¹⁰⁶ This brings to mind the origin of the term 'handicapped', which captures the idea of a person with 'cap-in-hand' being the recipient of charity.¹⁰⁷

1.2.B Losing sight of the individual

The second problem the medical model has is its depersonalising effect. It results in the medical condition coming into focus first rather than the person. The person is identified with his or her condition and objectified as a problem that needs to be fixed. Consequently, the condition is located as a problem of the individual.¹⁰⁸ This is what brought about the evolution of terms like 'cripple,' 'spastic,' 'invalid' and 'retarded'.¹⁰⁹ As illustrated in the introduction, this is what resulted in my son's decision to stop visiting unfamiliar churches because he felt he was invisible as a person.

¹⁰³ Charlton, p. 30.

¹⁰⁴ Charlton, p. 31.

¹⁰⁵ Charlton, p. 36.

¹⁰⁶ Creamer, *Disability and Christian Theology*, p. 24.

¹⁰⁷ Wayne Morris, *Theology Without Words: Theology in the Deaf Community* (Aldershot, England ; Burlington, VT: Ashgate Publishing Limited, 2008), p. 5.

¹⁰⁸ Eiesland, p. 53.

¹⁰⁹ Creamer, *Disability and Christian Theology*, p. 22.

In an attempt to bring a counterbalance to this negative portrayal of the individual, 'people first' terminology has become more popular.¹¹⁰ The phrase 'people with disabilities' is perhaps the most successful attempt at putting the person first and placing a focus on the individual and the common humanity that we all share.¹¹¹ Admittedly, however, even this terminology is strongly contested by some disability rights organisations. Hence the Union of the Physically Impaired Against Segregation,¹¹² for example, are quite adamant that 'disabled people' is the only correct term to use, as it places disability firmly as the responsibility of society and not the person.

In contrast to these disability rights organisations, writers such as Nancy Eiesland, who identifies herself as a woman with disabilities, alleges that 'people first' terminology is preferred by most disabled people themselves.¹¹³ Furthermore, I would say that for many lay people who are unaware of the political definitions, 'disabled people' seems to have more of a negative connotation and gives the impression of putting the emphasis on what the person is unable to do.

Despite this disagreement over terminology, there is still a challenge over losing sight of the individual that needs to be met. Creamer observes that the Christian church often speaks of the disability first when referring to people with disabilities, which has the unfortunate consequence of them being admired, pitied or even avoided, rather than being seen as people first.¹¹⁴

1.2.C Measuring normality

The third problem of the medical model centres on the idea of normality. Unfortunately, saying that someone 'has' a problem very easily leads to the next conclusion that they 'are' a problem.¹¹⁵ Often the notion of normality is proposed by the dominant majority as reflecting their way of functioning and being. This regrettably results in people with

¹¹⁰ Shakespeare, p. 19.

¹¹¹ For example, see the 'United Nations Convention on the Rights of Persons with Disabilities,' <http://www.un.org/disabilities/convention/conventionfull.shtml> (accessed 18 January 2017)

¹¹² UPIAS. For their policy statement see <http://disability-studies.leeds.ac.uk/files/library/UPIAS-UPIAS.pdf> (accessed 18 January 2017).

¹¹³ Eiesland, p. 27.

¹¹⁴ Creamer, *Disability and Christian Theology*, p. 59.

¹¹⁵ Creamer, *Disability and Christian Theology*, p. 24.

disabilities becoming the 'other' as a result of the 'normate' biases with which we judge others. The term normate,

Designates the social figure through which people can represent themselves as definitive human beings. Normate, then, is the constructed identity of those who, by way of the bodily configurations and cultural capital they assume, can step into a position of authority and wield the power it grants them.¹¹⁶

While challenging the concept of inclusion and proposing that it does not go far enough in its attempts to remove the alienation and stigmatization that wearing the label 'disabled' brings, Swinton concludes that difference is the norm.¹¹⁷ He makes the valid point that the designation 'disability' is a very limiting and unnatural one. For the sake of expediency it may be useful to categorise people as disabled thus making it easier to assign funds to a general group. However, the range of conditions that are identified as disabilities is so vast that it is difficult to see what people suffering with conditions such as paraplegia, cystic fibrosis and autism actually have in common.

Swinton goes on to contend that superficial understandings of people that only describe the shallow and obvious, also result in superficial forms of inclusion. Hence his conclusion that more individual and personal descriptions and understandings of people are necessary. Such rich understandings of individuals will most likely lead to a sense of truly belonging to a community, that is, being missed when you are not present, as opposed to merely being included because you happen to be present.¹¹⁸

Creamer also addresses the idea of normality when she points out that limits are part of our creation and should not be seen as sinful and therefore needing to be fought against in order to achieve perfection. Instead we should accept that limits are just part of being human and we should therefore question why we label some limits as normal and others as abnormal.¹¹⁹ Consequently, she offers an interesting definition of sin as, 'An inappropriate

¹¹⁶ Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997), p. 8.

¹¹⁷ Swinton, 'From Inclusion to Belonging', p. 178.

¹¹⁸ Swinton, 'From Inclusion to Belonging', p. 183.

¹¹⁹ Deborah Beth Creamer, 'Theology and Chronic Pain: Some Initial Reflections', *Journal of Religion, Disability & Health*, 17.2 (2013), 212–19 (p. 213) <<https://doi.org/DOI: 10.1080/15228967.2013.778516>>.

attitude toward limitness as we both exaggerate and also reject our own limits and the limits of others.’¹²⁰ This definition can readily be recognised in the Genesis account of Adam and Eve who sinned by overstepping the limit that God had given them.

Thus, the advantages and disadvantages of the medical model show that while a definition of disability needs to acknowledge the significance of biological factors, in order to avoid the consequences of controlling power and ideas of normalcy, it would be inadequate as the sole basis for such a definition. In order to promote personhood above medical conditions a different model is needed.

2. Defining Disability Socially

Having started in the medical field, the disability discourse began to change when people with disabilities set about challenging the prevailing medical model of classification that had resulted in the label ‘disability’. Beginning with a person’s pathology as a means of finding labels and definitions had resulted in the lived experience of people with disabilities being described as marginalising and oppressive, so other language was being sought.

2.1 Advantages of a social definition

By making a distinction between impairment and disability, it was found that disability could be seen as a social construct, a category that is imposed on an individual by society. For example, Creamer offers distinctions between ‘impairment’, ‘disability’ and ‘handicap.’¹²¹ Hence it is possible to speak of impairment being located in the physiological, disability being the social result of the impairment, and handicap being the disadvantage that comes from the impairment or disability. The importance of this is to be aware that ‘an impairment does not necessarily result in a disability, and a disability need not be a handicap.’¹²²

¹²⁰ Deborah Creamer, ‘Toward a Theology That Includes the Human Experience of Disability’, *Journal of Religion, Disability & Health*, 7.3 (2003), 57–67 (p. 66) <https://doi.org/10.1300/J095v07n03_05>.

¹²¹ Creamer, *Disability and Christian Theology*, pp. 13–14.

¹²² Creamer, *Disability and Christian Theology*, p. 14.

This way of distinguishing between impairment and disability gained momentum in the nineteen seventies and resulted in the formation of a number of disability organisations such as The Disability Alliance¹²³ and UPIAS¹²⁴ in Britain. In a document entitled '*Fundamental Principles of Disability*' it is stated that,

Disability is a situation, caused by social conditions.... In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society.¹²⁵

As a result, the term 'disabled people' came to be used as the label of choice by these activist groups. In disability studies this is known as the 'social model' of disability. In other words, being 'abled' or 'disabled' is primarily a result of social structures. This makes disability the responsibility of society and not the individual.

This idea was seen as a huge step forward in the fight for the liberation of disabled people. Charlton, for example, defines oppression as being 'when individuals are systematically subjected to political, economic, cultural, or social degradation because they belong to a social group'.¹²⁶ He goes on to show that disability oppression has three components: political-economic, cultural and an unhealthy consciousness.¹²⁷

The political economy identifies people according to their ability to contribute to economic production, thus grouping them into classes of power and privilege. In this sense Charlton says that people with disabilities are much more like outcasts because they often end up outside the general group of labourers and are dependent on charity for their survival. In fact he quotes a United Nations report that 'Handicapped people remain outcasts around

¹²³ In the words of Peter Townsend, the Alliance's chairman, "The Disability Alliance came into being as an umbrella organisation, primarily concerned with public education and therefore the issuing of information in pamphlet form, etc; and secondly as a more authoritative body concerned with pressure, authoritative in the sense that it could decently claim to be speaking on behalf of the majority of organisations concerned with disabled people." See <http://disability-studies.leeds.ac.uk/files/library/UPIAS-fundamental-principles.pdf> p.6 (accessed 18 January 2017).

¹²⁴ Union of the Physically Impaired Against Segregation.

¹²⁵ See <http://disability-studies.leeds.ac.uk/files/library/UPIAS-fundamental-principles.pdf> p.4. (accessed 18 January 2017)

¹²⁶ Charlton, p. 8.

¹²⁷ Charlton, p. 22.

the world, living in shame and squalor among populations lacking not only in resources to help them but also in understanding.’¹²⁸

When it comes to the cultural element of disability oppression, Charlton acknowledges that even though culture may be difficult to define:

The point is not that one culture makes people do or think this and another that but that ideas and beliefs are informed by and in cultures and that cultures are partial expressions of a world in which the dualities of domination/subordination, superiority/inferiority, normality/abnormality are relentlessly reinforced and legitimized.¹²⁹

Hence his thesis is that disability oppression produces a certain culture rather than being produced by a culture. Thus the attitude of ableism is the cause of the problem of disability, not physical impairment.

As for the unhealthy consciousness component, he posits that ‘most people with disabilities actually come to believe they are less normal, less capable than others.’¹³⁰ This is because they have internalised the messages that they have been constantly fed by the dominant culture that reflects values of how natural the dichotomy of superiority and inferiority are. The Brazilian educator and philosopher, Paulo Freire, would call this ‘prescription’.¹³¹ This is where one individual’s choice is forced upon another, thus making the oppressed conform to the ideas of the oppressor. The behaviour of the oppressed is prescribed because they internalise the images and language that the oppressor uses.

2.2 Disadvantages of a purely social definition

The social model has resulted in huge advances for people with disabilities. It has led to political liberation and law-based equality for people with disabilities. However, like the medical model, it too has serious limitations. We will consider two such disadvantages.

¹²⁸ Charlton, p. 21.

¹²⁹ Charlton, p. 26.

¹³⁰ Charlton, p. 27.

¹³¹ Paulo Freire, *Pedagogy of the Oppressed*, Penguin Books, New rev. ed (London: Penguin Books, 1996), p. 29.

2.2.A Majoring in minority

One of the main effects of the social model is that it has portrayed people with disabilities as an oppressed minority group. In this sense it follows other groups who have suffered discrimination such as women, people of colour, lesbian and gay people. Herein lies the first of its challenges. If oppression is the primary way in which people with disabilities should be viewed, should these other oppressed groups also be included in the definition of disability?¹³²

Freire articulates the danger thus: 'In order for this struggle to have meaning, the oppressed must not, in seeking to regain their humanity (which is a way to create it), become in turn oppressors of the oppressors, but rather restorers of the humanity of both.'¹³³ The problem with proponents of a strict social model is that they end up replacing one hierarchy with another. Having fought against the privilege of the healthy over the disabled, they often end up privileging the oppressed over the oppressor.¹³⁴ Simply replacing one extreme with another is not the key to a lasting solution.

In fact, using the social model theologically can culminate in an exclusive stereotype where only those with certain forms of agency actually qualify. This is seen in the fact that some disabilities are more socially acceptable than others,¹³⁵ but as mentioned previously, it also results in a hierarchy of disability, where people with severe learning difficulties always end up at the bottom of the ladder.¹³⁶

Perhaps the greatest limitation arising from the minority emphasis of the social model is that while it may be able to bring about changes in law to make physical accessibility possible, thus removing oppressive and unjust structures, once these are in place it has little more that it can do. Once injustices are removed, continuing to think of disability from a minority point of view has very little impact on people's attitudes.

The experience of my son Espen can serve as a good illustration of this. I remember asking him about what I had observed as his somewhat guarded attitude towards people who, to

¹³² Swinton, 'From Inclusion to Belonging', p. 175.

¹³³ Freire, p. 26.

¹³⁴ Creamer, *Disability and Christian Theology*, p. 30.

¹³⁵ Creamer, *Disability and Christian Theology*, p. 15.

¹³⁶ Reinders, pp. 24–27.

me, seemed to be well meaning. In response, he recounted to me that his defence mechanism of scepticism and holding people at arm's length had most likely come about as a result of the shocking admission of one of his friends at school. This 'friend' had admitted that he did not really like Espen, but felt that he had to hang around because "he couldn't be mean to a disabled person." In other words, he felt obligated to be nice and was only being polite because he was conforming to some social norm that dictated niceness towards people with disabilities.

2.2.B Ignoring individual experience

Because of its focus on ableism, the social model seems to downplay the very real physical and emotional impact of impairments. Tom Shakespeare is one author who has written a thought-provoking critique of this aspect of the social model. He describes the perspective he has gained from both acquiring an impairment (becoming paralysed) and having a congenital impairment (achondroplasia).¹³⁷

From a political perspective, Shakespeare points out that in assuming the common experience of oppression as the primary way of distinguishing disabled people, proponents of the social model end up making impairment-specific organisations superfluous.¹³⁸ This would obviously undermine the invaluable work that support groups provide. In fact, if taken to its logical conclusion, the minority rights view would treat all attempts to cure or rehabilitate medical conditions with extreme scepticism.¹³⁹

Shakespeare suggests that there should not be such a sharp dichotomy drawn between impairment and social factors because it is extremely difficult to distinguish between impairment and disability when it comes to the lived experience of people with disabilities.¹⁴⁰ He proposes instead that disability be seen as 'a complex interaction of biological, psychological, cultural and socio-political factors, which cannot be extricated except with imprecision'.¹⁴¹

¹³⁷ Shakespeare, p. 6.

¹³⁸ Shakespeare, p. 17.

¹³⁹ Shakespeare, p. 18.

¹⁴⁰ Shakespeare, p. 23.

¹⁴¹ Shakespeare, p. 26.

Furthermore, although it may seem natural to draw parallels between disability and sexism, racism and homophobia, Shakespeare argues that being disabled is different from the others because impairments themselves are limiting and not just neutral. 'Gender, race and sexuality have minimal biological underpinning. However, disability always has a biological dimension that usually entails limitation or incapacity, and sometimes frailty and pain.'¹⁴²

Thus, people with disabilities can be said to be in a special category of their own because they have less flexibility and fewer choices than those who are non-disabled. The others can be said to be neutral and only problematized by sexists, racists or the homophobic. Whereas, even though the removal of barriers in an environment may lessen the inconvenience of impairment, it does not make disabled and non-disabled people equal.

Therefore, we can summarise the forgoing arguments to say that a definition of disability must acknowledge the role of the socio-political environment in which we all live.

Nevertheless, a purely social definition would be an insufficient descriptor because it needs to attend to the reality of personal physical and emotional consequences. In other words, a suitable working definition will need to go beyond the medical and social models.

3. Defining Disability Experientially

Even though the medical and social models have long provided the dominant discourse for understanding and theorising disability, postmodern reasoning has now moved the discussion beyond this binary. Instead, disability is being understood as the sum of complex interrelations between a person and their surroundings.

3.1 Anthropological definitions

In her analysis of Brock and Swinton's *Disability in the Christian Tradition: A Reader*,¹⁴³

Elisabeth Antus observes that there are two anthropological positions from which past and

¹⁴² Shakespeare, p. 49.

¹⁴³ Brian Brock and John Swinton, *Disability in the Christian Tradition: A Reader* (Michigan: Wm. B. Eerdmans Publishing, 2012).

present authors attempt to define disability.¹⁴⁴ Firstly, there is the ‘Discourse of enfoldings’, where people with disabilities are included in an already defined account of humanity.¹⁴⁵ Historical examples of this enfolding idea can be found in the writings of Augustine, Thomas Aquinas and G.W.F. Hegel. In this category we will consider those who write from a realist perspective such as Tom Shakespeare and James Barton Gould.

Antus’ second category of authors are those who engage in a ‘Discourse of expansion’.¹⁴⁶ This is where people with disabilities are at the centre of the definition of what it means to be human, which includes vulnerability, limitation and interdependence. In this group are included historical figures such as Julian of Norwich and Martin Luther. Of those modern-day authors who propose a complete reworking of the idea of limitation to include every human being, Deborah Beth Creamer will serve as a good example.

3.1.A Realist accounts of disability

Tom Shakespeare critiques the dichotomy that has arisen between the social and medical models. He says a more fruitful approach would be a mixture of both models in what he calls a ‘critical realist approach’.¹⁴⁷ For him:

Critical realists distinguish between ontology (what exists) and epistemology (our ideas about what exists). They believe that there are objects independent of knowledge: labels describe, rather than constitute, disease. In other words, while different cultures have different views or beliefs or attitudes to disability, impairment has always existed and has its own experiential reality.¹⁴⁸

His main problem with the social model is that it magnifies the importance of the extrinsic factors influencing disability, yet it downplays the significance of the factors that are intrinsic to the person. The result is that social model proponents neglect to take the experience of individual impairment into consideration. Thus he ends up defining disability as follows:

¹⁴⁴ Elizabeth L. Antus, ‘Disability at the Heart of Theology: On Marginality, Method, and Overcoming “Best-Case Anthropologies”’, *Journal of Religion, Disability & Health*, 17.3 (2013), 244–62 <<https://doi.org/10.1080/15228967.2013.809879>>.

¹⁴⁵ Antus, p. 247.

¹⁴⁶ Antus, p. 253.

¹⁴⁷ Shakespeare, p. 25.

¹⁴⁸ Shakespeare, p. 73.

Disability is always the combination of a certain set of physical or mental attributes, in a particular physical environment, within a specified social relationship, played out within a broader cultural and political context, which combines to create the experience of disability for any individual or group of individuals.¹⁴⁹

He suggests viewing impairment as a predicament, which although unpleasant and trying, does not have the connotation of being tragic. 'To call something a predicament is to understand it as a difficulty, and as a challenge, and as something that we might want to minimise but which we cannot ultimately avoid.'¹⁵⁰

Hence, Shakespeare's perspective on disability uses a realist approach that places the subjective experience of impairment at its centre rather than merely relying on philosophical surmising about disability.

The main challenge with this model is that in emphasising the physical difficulties of impairments, the author may be interpreted as acquiescing to an ideal norm for physical function. As shown above, the identification of such a norm is generally seen as problematic in disability literature. Nevertheless, some believe that the Christian account of creation opens up for the concept of a functional norm.

Gould argues from the perspective of a father of a son with severe learning difficulties. He makes the distinction between inabilities, which are normal limits for humans (being unable to fly for example), and disabilities, which he sees as 'departures from species-typical functioning.'¹⁵¹ This is based on viewing creation as providing what could be called a 'normal species function' model, where creatures were designed featuring structures and processes that were typical for their species to flourish.

In seeking to counter the criticism of what constitutes normality, Gould categorically states that people with disabilities do enjoy good lives notwithstanding their disability. 'Being unable to function in a species-typical manner does not necessarily mean being unable to flourish as a human being; many people with disabilities work and love, have a full

¹⁴⁹ Shakespeare, p. 78.

¹⁵⁰ Shakespeare, p. 86.

¹⁵¹ James Barton Gould, 'The Hope of Heavenly Healing of Disability Part 1: Theological Issues', *Journal of Disability & Religion*, 20.4 (2016), 317–34 (p. 319) <<https://doi.org/10.1080/23312521.2016.1239153>>.

emotional range and enjoy rich and meaningful lives.’¹⁵² From a subjective perspective the lives of people with and without disabilities are equal. But his argument is that a person with disability could be said to have an objectively better life if they did not have the disability. In other words, he is arguing for a realist account of disability where actual deficiencies in typical human functioning are experienced, rather than merely seeing disability as a theoretical category.

The ideas of both Shakespeare and Gould illustrate the challenge of enfolding definitions of disability. Realism can be seen as veering towards the individualising trap of the medical model where disability becomes the problem of the individual. Nevertheless, realism does show that a definition needs to reflect the reality of the physical, emotional and psychological experiences of a person with disability.

3.1.B Disability at the centre of humanness

In the introduction to her book, *Disability and Christian Theology*, Deborah Beth Creamer makes the bold statement that ‘disability may be a category that is no longer relevant in a postmodern world.’¹⁵³ Her model is an attempt to attend to the medical and social models but then to go beyond them by reflecting on the consequences of the fact that we all live embodied lives. Consequently, she proposes a limits model that recognises that, “Disability” is actually more normal than any other state of embodiedness. As such, disability should not be an afterthought to models of embodiment.’¹⁵⁴

Creamer is careful to point out the difference between the terms ‘limited’ and ‘limits’. ‘The term “limited” is often taken as representing something that is unfortunate and emphasizing that which is “not.” The term “limits,” on the other hand, places the emphasis on boundaries.’¹⁵⁵ This then leads her to describe limits using three adjectives: unsurprising, intrinsic and good (at least not evil). Thus, since we all live lives with limits, it should be viewed as the norm for human experience:

¹⁵² James Barton Gould, ‘The Hope of Heavenly Healing of Disability Part 2—Philosophical Issues’, *Journal of Disability & Religion*, 21.1 (2017), 98–116 (p. 101) <<https://doi.org/10.1080/23312521.2016.1270177>>.

¹⁵³ Creamer, *Disability and Christian Theology*, p. 7.

¹⁵⁴ Creamer, *Disability and Christian Theology*, p. 32.

¹⁵⁵ Creamer, *Disability and Christian Theology*, p. 94.

Limits are a normal and unsurprising aspect of life. Yet we choose, for whatever reason, to stigmatize some and normalize others. When we dismiss disability as being an exceptional and othering experience, we deny the normality of limits in all of our lives, pretend that we do not experience increasing limits as we age, and even refuse to acknowledge the future limit of death.¹⁵⁶

In other words, the idea of human embodied limits is an argument for viewing disability as a form of human biodiversity that is as welcomed and accepted as any other forms of diversity.

Fortunately, Creamer does call attention to the fact that accepting limits does not mean that we should not attempt to overcome them or adapt to them.¹⁵⁷ However, here is perhaps one of the potential weaknesses of her model. We are left with the question of how to decide which limits to try to overcome and which ones to accept. Even though deaf people, for example, have chosen to accept their limits, does this mean it would be wrong to offer cochlear implants to improve the possibility of hearing? This model of the universality of human limits may provide a fruitful starting point from which to begin reflecting on disability, but more is needed to guide us to what this would mean in practice.

Thus, it can be seen that an expansion anthropology aims to eliminate the them/us dichotomy between abled and disabled by arguing that vulnerability and fragility are central to what it means to be human. While this is an admirable ideal, it is unlikely to work as a stand-alone strategy. If the reality of disability is to be adequately tackled, it is important to be able to name the difference.¹⁵⁸ It is unlikely that ableist attitudes will be removed by merely attempting to have everyone accept that we are all disabled.

Perhaps the effort to arrive at a common humanity can be strengthened by teaching people how to welcome difference. Young, for example, proposes the Christian community as a model for a better way because they are constantly reminded in the Bible that they are to live as resident aliens. 'They live as aliens, sharing in everything as citizens, and enduring

¹⁵⁶ Creamer, *Disability and Christian Theology*, p. 119.

¹⁵⁷ Creamer, *Disability and Christian Theology*, p. 109.

¹⁵⁸ Young, *Brokenness and Blessing*, p. 94.

everything as foreigners.’¹⁵⁹ She uses this to make the point that people with disabilities reveal who we really are – that we have the soul of the resident alien. In other words, we should learn to welcome difference because we are all different.

3.2 Defining disability intersectionally

Intersectionality is the attempt to describe the complexity of identity. As first elaborated by Crenshaw in 1989, it said that laws were being enforced in a discriminating way because they were based on single aspects of identity such as race or sex. Instead, a person’s identity should take into consideration the varied intersecting aspects of their identity, thus resulting in a more comprehensive understanding of the complexity of identity.¹⁶⁰

3.2.A Disability and feminism

The intersection of disability and feminism has highlighted a number of issues that have been confronted. Feminist writers point out that the norm for bodies is white, male and able-bodied, with all variants of this being seen as aberrant.¹⁶¹ Further to this, women with disabilities have had to fight to have their viewpoints recognised in both the disabled people’s movement and the women’s movement.¹⁶² To the disabled people’s movement their assertion was that since the issues they faced were different from those encountered by disabled men, people with disabilities should not be thought of as a homogenous group. On the other hand, the shortcomings of mainstream feminists were highlighted to show how they tended to exclude the experience of disabled women by perpetuating the ableist stereotypes of disabled women as dependent and needy.¹⁶³

The maxim ‘the personal is political’ has been used by disabled feminists to highlight the unique personal experiences of women with disabilities. Susan Wendell, for example, shows that disability is often conceived from an objective perspective as a clearly identifiable and stable category, but she argues that it is much more complex and

¹⁵⁹ Young, *Brokenness and Blessing*, p. 91.

¹⁶⁰ *Intersectionality and beyond: Law, Power and the Politics of Location*, ed. by Emily Grabham (Abingdon: Routledge-Cavendish, 2009), p. 124.

¹⁶¹ Rosemarie Garland-Thomson, ‘Misfits: A Feminist Materialist Disability Concept’, *Hypatia*, 26.3, Ethics of Embodiment (2011), 591–609.

¹⁶² Watson, Roulstone, and Thomas, p. 363.

¹⁶³ Jenny Morris.

nuanced.¹⁶⁴ Especially the idea of ‘epistemic invalidation’¹⁶⁵ shows how a personal knowledge of the experience of one’s own body is rejected by biomedicine who provide their own authoritative discourse for what is considered to be valid.

For definitional purposes the benefit of the intersection between feminism and disability is that it speaks of the necessity of viewing disability as a complex and diverse experience.

3.2.B Disability and race

One of the first issues that the intersection of race and disability has revealed is that the minority rights model is primarily based on the experiences of white, middle-class people and as such is a form of ‘disability essentialism’ which assumes that the experience of disability is one uniform experience.¹⁶⁶ Thus, arguing against the medical model is an easier choice for white, middle-class people than for black people who have not had the privilege of enjoying quality medical care.

Research has found that disability and racial disparity results in many disadvantages for minority ethnic cultures such as earlier onset of disability, more rapid decline in functioning, and children from ethnic minority cultures being placed into special education in disproportionately higher numbers.¹⁶⁷ This underscores the lived experience of people inhabiting both of these modalities as one of being socially invisible and an outsider to mainstream society. Thus, for example a Canadian research found that if you are an able-bodied refugee you may get a low paid job, but if you are a person with disability you are assumed to be unfit for employment and thus unwanted.¹⁶⁸ Another aspect of the experience of disability and race is seen in the ways social restraint and containment are more frequently used to impose limits on people with disabilities from ethnic minorities.¹⁶⁹

¹⁶⁴ Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996).

¹⁶⁵ Wendell, p. 122.

¹⁶⁶ Angela Frederick and Dara Shifrer, ‘Race and Disability: From Analogy to Intersectionality’, *Sociology of Race and Ethnicity*, 2018, 233264921878348 (p. 4) <<https://doi.org/10.1177/2332649218783480>>.

¹⁶⁷ Watson, Roulstone, and Thomas, p. 379.

¹⁶⁸ Parin Dossa, ‘Racialized Bodies, Disabling Worlds “They [Service Providers] Always Saw Me as a Client, Not as a Worker”’, *Social Science & Medicine*, 60.11 (2005), 2527–36 <<https://doi.org/10.1016/j.socscimed.2004.11.011>>.

¹⁶⁹ Watson, Roulstone, and Thomas, pp. 383–84.

The use of disability as a metaphor has also been found to be problematic. Thus, because disability was often seen as being synonymous with defectiveness and deviance from the norm, it came to be used as a description for blacks, immigrants, women and the poor.¹⁷⁰ On the other hand, the use of disability as a metaphor in the struggle for black emancipation eventually led to a distancing between race and disability in order to show the normalcy of race.¹⁷¹ Invariably this metaphorical use of disability made the actual disability invisible.

These two examples of intersectional discourse are sufficient to illustrate the many complexities that comprise identity. They also speak to the fact that a static definition of disability will always be inadequate because we are not dealing with a fixed and clearly bounded category.

Conclusion

This discussion of terminology forces us to acknowledge that the pursuit of a definition of disability is a complex and problematic endeavour. Having explored the medical, social and experiential elements that should influence the formulation of a definition from which to build an Adventist disability ministry, I believe it is necessary to be aware that disability is used both ontologically and epistemologically. Further to this I believe a definition should help people realise that disability is not the simple problem of an individual but is rather the result of a complex combination of a number of different factors. Hence, I would like to offer the following as a starting point for a working definition that will need to be modified and adjusted as time goes on:

Disability is a lived experience (ontological) and a way of categorising experience (epistemological). Ontologically, disability is the experience of limit arising from the combination of a person's departure from species-typical functioning and the environment in which they function. Epistemologically, disability is a way of categorising human limit that particularly accounts for biological, psychological, cultural and socio-political factors.

¹⁷⁰ Frederick and Shifrer, p. 7.

¹⁷¹ Frederick and Shifrer, p. 8.

Chapter 4 – Methodology

The research questions that form the basis of this thesis all centre around how the SDA church can authentically engage with its members who live with various disabilities. From a theological perspective I would propose that they are all based in the field of practical theology. Although this is a rich discipline which embraces a wide range of methods, concerns and participants, I believe it lends itself to this thesis because it gives particular significance to human experience. Practical theology not only acknowledges that faith is something that is believed but that it is also something to be lived.¹⁷²

In her reference guide, Bonnie J. Miller-McLemore condenses practical theology in the following way:

Practical theology as a term refers to at least four distinct enterprises with different audiences and objectives, the two just named: it is a *discipline* among scholars and an *activity of faith* among believers. And it has two other common uses: it is a *method* for studying theology in practice and it is a *curricular area* of subdisciplines in the seminary.¹⁷³

These four interrelated areas show the complex and wide-ranging field that practical theology spans.

My study covers at least two of these uses. First of all, it will show that practical theological reasoning is the activity that SDA church believers will need to engage in as they reflect on how their faith can be lived out in the context of disability. Secondly, this study will illustrate practical theology as the method to be used to examine how Adventist theology can be put into practice as it meets the opportunity of disability. The result will be the gaining of practical wisdom or ‘phronesis’ which, it is hoped, will directly affect and transform the praxis of individuals, local congregations and the SDA community at large.¹⁷⁴

¹⁷² John Swinton and Harriet Mowat, *Practical Theology and Qualitative Research Methods* (London: SCM Press, 2006), p. 5.

¹⁷³ *The Wiley-Blackwell Companion to Practical Theology*, ed. by Bonnie J. Miller-McLemore (Chichester: Wiley-Blackwell, 2012), p. 5.

¹⁷⁴ Swinton and Mowat, p. 26.

Since this transformative feature of practical theology is achieved as a result of critical and theological reflection on practice,¹⁷⁵ this chapter will seek to clarify the methodology by which this reflection will be done.

Scholars have pointed out that human beings are inherently hermeneutical.¹⁷⁶ In other words, we are constantly interpreting experiences and situations. Don Browning observes that human thinking does not move from theory to practice because, 'theory is always embedded in practice.'¹⁷⁷ Therefore, our thought processes move from practice to theory and back to practice again. Consequently, he argues that all theology can be practical if we bring to it our practical concerns at the beginning.¹⁷⁸ In other words, we do not start theology from a blank slate but bring to it questions that have been shaped by our practices. When circumstances force us to ask questions about our practices, which even though they come naturally to us are always theory-laden, then we turn to those texts and sources that we deem authoritative to re-examine them and then formulate new understandings and practices. This state of being continues until a new crisis forces the process to begin again.¹⁷⁹ Thus, practical theology has a circular structure moving from practice to theory and back to practice again.¹⁸⁰

Further to this, Browning argues that practical reason endeavours to answer the question, 'How should we live?' This is in contrast to theoretical reason, which asks, 'What is the nature of things?' or technical reason which asks, 'What are the most effective means to a given end?'¹⁸¹ Since my research questions fall under the basic enquiry of practical reason, my methodology will come from practical theology which will have a hermeneutical circular structure to it. Within practical theology the most common form of this has come to be known as the pastoral cycle.

¹⁷⁵ Swinton and Mowat, pp. 6–9.

¹⁷⁶ Swinton and Mowat, p. 147.

¹⁷⁷ Don S. Browning, *A Fundamental Practical Theology: Descriptive and Strategic Proposals* (Minneapolis: Augsburg Fortress, 1991), p. 9.

¹⁷⁸ Browning, p. 5. In fact he goes on to argue that because practical thinking is at the centre of human thinking, and theoretical and technical thinking are derivatives of practical thinking, then what he calls 'fundamental practical theology' is the all-encompassing theological discipline which subsumes the four subgroups of descriptive theology, historical theology, systematic theology and strategic practical theology.

¹⁷⁹ Browning, p. 6.

¹⁸⁰ This is in contrast to the Barthian model of theology which moves in a more linear fashion from theory to practice.

¹⁸¹ Browning, p. 10.

1. The Pastoral Cycle

Some scholars, such as Ballard and Pritchard, propose that the pastoral cycle, which is said to have originated in liberation theology, should be at the centre of all modern-day applications of practical theology.¹⁸² The cycle is generally seen to have four basic points to it,¹⁸³ the first of which is experience. This describes an event or occurrence that disturbs the current status quo and prompts questions that need to be explored. Thus for example, for Ballard and Pritchard, experience includes three processes: gathering information and attending to experience, recording information and experience, and shaping information and experience for presentation.

Exploration is the second point of the cycle and this is where information is gathered about what is going on. In this stage theories from the social sciences in particular are used to assess and analyse the experience that is being investigated in order to get a clearer understanding of the situation.

Reflection is the third step and this describes the process of bringing theological perceptions, beliefs and values face to face with the contemporary situation. Lartey, for example, prefers to divide this step into two separate parts so he ends up with a five-part cycle.¹⁸⁴ First is what he calls 'theological analysis', which basically asks how thinkers in one's particular faith tradition have approached the issue in question. Second is 'situational analysis of theology' which seeks to find out how adequate the tradition's formulation is in responding to the concrete experience that has been encountered.¹⁸⁵ Although these two questions are quite important I do not see that they warrant separate steps in a cycle, but rather that they can be naturally incorporated into the same step of reflection.

¹⁸² Paul H. Ballard and John L. Pritchard, *Practical Theology in Action: Christian Thinking in the Service of the Church and Society* (London: SPCK, 1996), p. 74.

¹⁸³ Ballard and Pritchard, p. 77.

¹⁸⁴ Emmanuel Yartekwei Lartey, *In Living Colour: An Intercultural Approach to Pastoral Care and Counselling* (London: Cassell, 1997).

¹⁸⁵ Lartey, p. 103.

The final point in the pastoral cycle is action. This describes the resulting decisions and initiatives that are taken as a result of the foregoing process. Here it is worthwhile noting the observation of Swinton and Mowat:

For the practical theologian, action is not merely pragmatic or problem-solving, although it may contain elements of this. For the practical-theological action always has the goal of interacting with situations and challenging practices in order that individuals and communities can be enabled to remain faithful to God and to participate faithfully in God's continuing mission to the world.¹⁸⁶

In other words, practical theological action can be said to have an arbitrating function in that it seeks to 'mediate between the practices of the Christian faith and the practices of the world'.¹⁸⁷

There are at least two observations that can be made about the pastoral cycle. Firstly, we need to acknowledge that the term 'cycle' can be somewhat misleading. It can give the impression of progression from one point to the next until the whole cycle is completed, whereas in actual fact, the flow of understanding moves backwards and forwards at each step. This accounts for the fact that most drawn illustrations of the cycle have two-way arrows between each step.¹⁸⁸ Furthermore, the cycle is really more like a spiral than a circle because the process is constantly being repeated.¹⁸⁹

The second observation is that it is interactive. By this I mean, the process inherent in the cycle is one in which different perspectives are brought together. Some theologians describe this as dialogical while others depict it as correlational. For example, in his chapter entitled, *'Some Straw for the Bricks: A Basic Introduction to Theological Reflection'*, Stephen Pattison introduces a model that he calls a 'mutual critical conversation'.¹⁹⁰ He suggests that a simple way of thinking through the relationship between situations and theological theories is to imagine oneself in a three-way conversation. The three conversation partners

¹⁸⁶ Swinton and Mowat, p. 257.

¹⁸⁷ Swinton and Mowat, p. 258.

¹⁸⁸ For example, see Swinton and Mowat p. 95.

¹⁸⁹ Richard R. Osmer, *Practical Theology: An Introduction* (Grand Rapids, MI: Eerdmans, 2008), p. 11.

¹⁹⁰ *The Blackwell Reader in Pastoral and Practical Theology*, ed. by James Woodward and Stephen Pattison, 1st Edition (Oxford: Blackwell Publishing Ltd, 2000), pp. 135–43.

are: one's own ideas and assumptions, the beliefs that come from the Christian tradition (which includes the Bible), and the contemporary situation that is being explored.

Browning is another proponent of a dialogical process. He defines fundamental practical theology as, 'Critical reflection on the church's dialogue with Christian sources and other communities of experience and interpretation with the aim of guiding its action toward social and individual transformation.'¹⁹¹ He also mentions the same three conversation partners entering into dialogue.

Understanding the dialogic nature of the pastoral cycle is a very useful way of conceptualising a methodology, but it still leaves the question of how one should go about formulating the guiding rules by which the conversation should proceed. Swinton and Mowat, for example, propose what is known as 'mutual critical correlation'. In this they acknowledge an indebtedness to Paul Tillich's method of correlation,¹⁹² albeit making it their own. They point out that any method that portrays theological truth as moving in one direction, providing scriptural answers for our questions, but not allowing the theological truths themselves to be questioned, will always be imbalanced. Hence there is always a need for an element of mutuality.

Nevertheless, this still does not address the challenge of the relationship of the mutual conversation partners. 'If mutuality truly means that both parties have an equal voice in the research process and that the social sciences can actually override theology on central issues, then the danger of idolatry becomes a real possibility.'¹⁹³ In order to resolve the dilemma of correlating situations, theology and social science, Swinton and Mowat suggest that hospitality, conversion and critical faithfulness are needed.¹⁹⁴

Hospitality describes the attitude of humble respect that a theologian needs when engaging qualitative research methods.

In being hospitable towards other forms of knowledge and alternative approaches to the world, the object is not to seek after the lowest common denominator within

¹⁹¹ Browning, p. 36.

¹⁹² Swinton and Mowat, pp. 77–79.

¹⁹³ Swinton and Mowat, p. 83.

¹⁹⁴ Swinton and Mowat, p. 91.

which dialogue can take place. It is rather to create a context wherein the voice of qualitative research can be heard, respected and taken seriously, but with no a-priori assumption that theology needs to merge, follow or fully accept the perspective on the world that is offered to it by qualitative research.¹⁹⁵

The metaphor of conversion is used to denote the need to Christianise some of the goals and assumptions of qualitative research, in order for it to be employed in the theological objective of making God's purposes known.¹⁹⁶ This is especially necessary in order to convert conclusions arising from an atheistic standpoint into applicable principles in a theistic worldview. Thirdly, critical faithfulness describes the overall approach of authentically holding all these processes together.¹⁹⁷

Thus, my methodology will be rooted in practical theology and follow the general dialogical processes of the pastoral cycle. Whilst finding Swinton and Mowat's presentation quite useful, the particular variation of the pastoral cycle that I have found to be most helpful and on which I will structure my methodology is that described by Richard Osmer in his book, *Practical Theology: An Introduction*, to which I now turn.

2. Osmer's Four Core Tasks of Practical Theology

Osmer proposes four questions that guide how we respond to various experiences in the church: What is going on? Why is this going on? What ought to be going on? How might we respond?¹⁹⁸ His central argument is that these questions introduce a way into what he sees as the four key tasks that all practical theological interpretation has to work through. These tasks are: the descriptive-empirical, the interpretive, the normative, and the pragmatic.¹⁹⁹

¹⁹⁵ Swinton and Mowat, p. 91.

¹⁹⁶ Swinton and Mowat, p. 92.

¹⁹⁷ Swinton and Mowat, p. 93.

¹⁹⁸ Osmer, p. 4.

¹⁹⁹ Osmer, p. 10.

2.1 The descriptive-empirical task

The descriptive-empirical task endeavours to answer the question ‘what is going on?’ This is not simply about gathering facts but is rather ‘grounded in a spirituality of presence’.²⁰⁰

Osmer articulates this as an act of priestly listening which describes ‘a spiritual orientation of attending to others in their particularity and otherness within the presence of God. The key term here is “attending,” relating to others with openness, attentiveness, and prayerfulness.’²⁰¹ Osmer understands attending as spanning a continuum from informal through semiformal to formal attending.²⁰² It is while explaining formal attending that Osmer goes into detail about empirical research design. He particularly believes that describing, observing and interviewing are important skills to learn in order to do good formal attending.²⁰³

2.2 The interpretive task

Following on from the descriptive-empirical task is the question, ‘why is this going on?’ which introduces the interpretive task. This is about doing theoretical interpretation of the data that has been collected and is ‘based on an attitude of openness to the world. It depends on a thinking faith willing to learn from the intellectual resources of contemporary culture.’²⁰⁴ For Osmer, this task requires spiritual leaders who display sagely wisdom as shown in Israel’s wisdom tradition and embodied in Jesus as the ultimate revelation of God’s hidden wisdom.

This sagely wisdom is said to incorporate the qualities of thoughtfulness, theoretical interpretation and wise judgment.²⁰⁵ Thoughtfulness involves a considerate insight into people and circumstances. Theoretical interpretation is the ability to draw from the different theories generated by the arts and sciences. Wise judgment corresponds to Aristotle’s concept of *phronesis* which is often translated as ‘practical wisdom’ and ‘prudence’. It is about understanding the relevant variables in a particular situation and

²⁰⁰ Osmer, p. 34.

²⁰¹ Osmer, p. 34.

²⁰² Osmer, p. 37.

²⁰³ Osmer, pp. 58–61.

²⁰⁴ Osmer, p. 93.

²⁰⁵ Osmer, p. 82.

being able to discern the right course of action to take. This necessarily requires some form of cross-disciplinary dialogue.

One of the main challenges with a multidisciplinary approach is to know which theories to dialogue with. Osmer suggests a 'communicative model of rationality' which he proposes has three parts.²⁰⁶ Firstly, it offers arguments for the specific claims that it makes. Secondly, it acknowledges that claims are always grounded in a particular perspective or position. Thirdly, theories are seen as 'fallible', which means that humility is needed to realise that a theory will be reconsidered in the light of other views and perspectives that are just as fallible.

With this as a background, Osmer gives three suggestions for analysing and evaluating theories. Firstly, 'identify and assess the model, or root metaphor, of a theory and the conceptual field built on this model.'²⁰⁷ So for example, in the case of disability it would be important to understand that perspectives based on the medical model would see disability as rooted in a functional deviation from an assumed norm. This then enables the enquirer to ask whether this model adequately describes the experience of disability. Osmer's second suggestion is to 'identify the disciplinary perspective a theory uses and the level of life this discipline addresses.'²⁰⁸ This would mean ascertaining whether a theory is based on medical science, psychology or sociology, for example. The reason why this is said to be important is that it acknowledges the limits of any given theory, thus highlighting the danger of reductionism, using one theory to explain everything, and the need for a multidisciplinary approach. Osmer's third suggestion is to 'identify and evaluate the central argument(s) of a theory.'²⁰⁹

From an Adventist perspective, Osmer's communicative model of rationality is not without its challenges, particularly when it comes to addressing issues of diversity. The SDA church is very multicultural, which, even though it brings much richness to the community, also presents a number of challenges when dealing with various issues. How should a church leader guide a church that is divided in the way it reasons and argues? For example,

²⁰⁶ Osmer, p. 102-103.

²⁰⁷ Osmer, p. 114.

²⁰⁸ Osmer, p. 117.

²⁰⁹ Osmer, p. 121.

generally speaking, the African way of evaluating situations is to think of spirits being more directly involved in everyday life. Thus, they will have a more natural tendency to associate certain disabilities with the involvement of spirits. The western European way, on the other hand, is to use more human rationalism resulting in a more scientific way of viewing disability. Therefore, when considering the subject of disability, it would be necessary for Adventist church leaders to be aware of how conflicting cultural attitudes towards disability would influence the way people with disabilities experience life in their local church communities.

2.3 The normative task

The third task as introduced by the question, 'What ought to be going on?' is the normative. Osmer likens this to the function of biblical prophets whose main role was to contextualise the divine revelation. 'It is appropriate, thus, to describe the interplay of divine disclosure and human shaping as prophetic discernment. The prophetic office is the discernment of God's word to the covenant people in a particular time and place.'²¹⁰

Osmer portrays the prophetic discernment of the normative task as progressing along three lines. Firstly, there is theological interpretation, which he defines as, 'interpretation of *present* episodes, situations, and contexts with theological concepts'.²¹¹ Secondly, there is the use of ethical norms for guiding and reflecting on practice. This is important because all action can be said to be value based. Thus, 'Ethical reflection with universal ethical principles is particularly important, for it allows moral communities to test their present practices and norms against universal ethical principles.'²¹² The third approach to normativity is to focus on examples of good practice. This can provide models of good practice from the present or the past, and it can create new ways of understanding God and the Christian life that transcend those given by the received tradition.²¹³

²¹⁰ Osmer, p. 133.

²¹¹ Osmer, p. 139.

²¹² Osmer, p. 149.

²¹³ Osmer, p. 152.

It is in this section that Osmer deals with some of the issues arising from the cross-disciplinary dialogue that theology has to engage in.²¹⁴ He notes four forms that this dialogue can take.²¹⁵ It can be intradisciplinary (between various perspectives in a single field), interdisciplinary (where two fields are brought together), multidisciplinary (where several fields are brought together simultaneously), or metadisciplinary (a dialogue about the nature of a discipline).

Speaking specifically about interdisciplinary and multidisciplinary dialogue, Osmer notes three models that are used to conceptualise the cross-disciplinary dialogue between theology and other fields. The first is the correlational model, where the dialogue is one of mutual influence.²¹⁶ The second is the transformational model, which is like a conversation where two different languages are being spoken so translation needs to occur. Thus, theology listens to other fields but 'transforms their insights according to the rules of its own theological grammar'.²¹⁷ The third is the transversal model, where there is overlap, intersection and convergence of disciplines that share some of the same perspectives and values and yet may be quite divergent in other ways.²¹⁸ This transversal model will be the way in which this thesis engages with the social sciences.

2.4 The pragmatic task

The final task of practical theological interpretation is to ask the question, 'How might we respond?' This pragmatic task deals with the issue of how to lead change. Consequently, Osmer looks at three forms of leadership. Firstly, there is task competence leadership which is 'The ability to excel in performing the tasks of a leadership role in an organization.'²¹⁹ Secondly, there is transactional leadership which is 'the ability to influence others through a process of trade-offs',²²⁰ that include political trade-offs when dealing with groups that have competing agendas. Thirdly, there is transforming leadership which

²¹⁴ He does underline the fact that the dialogue between theology and other fields is not limited to this task, but is part of all four tasks of practical theological interpretation. See p. 173.

²¹⁵ Osmer, p. 163.

²¹⁶ Osmer, p. 164.

²¹⁷ Osmer, p. 169.

²¹⁸ Osmer, p. 170.

²¹⁹ Osmer, p. 176.

²²⁰ Osmer, p. 176.

describes 'leading an organization through a process in which its identity, mission, culture, and operating procedures are fundamentally altered.'²²¹

It is particularly this example of leading deep change that brings out the spiritual metaphor of servant leadership. Drawing on the example of the Old Testament kings of Israel and the prophetic descriptions of the suffering servant, Osmer shows how this is applied to Jesus the Messiah in the New Testament. Thus, Christ becomes the embodiment of godly servanthood. This is significant because as he notes, 'Servant leadership is leadership that influences the congregation to change in ways that more fully embody the servanthood of Christ. It is not primarily a matter of personality traits, like being self-effacing, mild-mannered, or overly responsible.'²²²

Osmer engages with literature describing organisation change as an interdisciplinary dialogue partner, to illustrate three important questions that 'open systems theory' helps leaders ask.²²³ What vision of congregational change best captures the mission of the congregation in its particular context? What sort of process of change is needed in my congregation: revolutionary or evolutionary change? How might I support change at different levels of the congregation? This is used to again effectively underscore his argument of the importance of cross-disciplinary dialogue during the whole practical theological process.

One of the elements that drew me to Osmer's methodology was his emphasis on helping congregations to model the spiritual leadership of Christ as priest, king and prophet.²²⁴ This explains why he refers to ministers as 'interpretive guides' and congregations as 'communities of interpretation' throughout the book. His thoroughly biblical rationale for each of the four core tasks would make his method much more palatable for Adventists, especially in the light of the fact that they, like other evangelicals, are devoted to understanding how the Bible speaks to contemporary situations. There is among many Adventist members a deep-seated scepticism towards depending on non-biblical sources in order to understand current situations, thus teaching congregations to develop skills in

²²¹ Osmer, p. 177.

²²² Osmer, p. 192.

²²³ Osmer, pp. 201–3.

²²⁴ Osmer, p. 28.

priestly listening, sagely wisdom, prophetic discernment and servant leadership would be very appealing.

Paradoxically though, this is perhaps one area in which Osmer's method could be critiqued. If his book is meant to be a resource for congregational leaders, his emphasis on describing how theology should dialogue with other disciplines can give a somewhat imbalanced impression. For example, in describing the descriptive-empirical task he uses most of the chapter to describe the mechanics of formal attending through empirical research. While this is a goldmine for academic researchers it can also come across as somewhat overwhelming for a congregational leader without theological training, which is often the case in local Adventist churches. This would inevitably limit the extent to which it could influence a wider audience.

As a further note of critique, Osmer is clearly a proponent of a multidisciplinary methodology, however he does not seem to address the challenge of individual bias. Even though we may think we are being objective and rational in considering different fields to dialogue with, we are all prone to individual biases, favouring certain argument over others. The solution for this, I believe, lies in good reflexive practice where one's biases are acknowledged and openly stated, in a context of shared conversation with one's peers and colleagues.

On the whole, I believe the clarity of Osmer's four guiding questions and the biblical foundation of the four spiritual metaphors not only functions effectively, but will also have a natural appeal in an Adventist setting. Thus, in the ensuing chapters the research question will be explored using the four tasks of practical theology, with particular emphasis on the four spiritual metaphors.

Chapter 5 – Living with Disability in the Adventist Church

(The descriptive-empirical task)

The goal of this chapter is to describe how I performed the task of priestly listening, and to present the data that was collected as a result of performing this task. This will serve to model for the SDA community the importance of making this its first response to people with disabilities, and will provide the data from which to further explore the research question.

The task of priestly listening is about understanding how a community can learn to attend to those with disabilities in its midst. Osmer describes attending as ‘relating to others with openness, attentiveness, and prayerfulness’,²²⁵ and it can range from informal, through semi-formal to formal attending.²²⁶

Informal attending would include teaching church members active listening skills to increase their everyday attentiveness to others. Semi-formal attending would involve more structured and regular attentiveness such as journaling or reflecting in board meetings on what is happening in the lives of certain people in a congregation. Formal attending involves investigating certain episodes or occurrences through empirical research, of which this chapter will serve as an example.

Beginning with this task was important in order to avoid the pitfall of paternalism which easily becomes the default attitude in Christian circles. Authors such as McCloughry lament the fact that the Christian church often fails to listen to people with disabilities. ‘One of the most disabling activities in life happens when others debate the meaning of your life without consulting you about it. Yet this is repeatedly done to disabled people.’²²⁷

To avoid this study being labelled as another ‘disabling activity’, this chapter will describe the empirical research which I did for my Ministerial Focused Study.²²⁸ This is based on an agreement with Osmer’s observation that ‘Empirical research is a disciplined way of

²²⁵ Osmer, p. 34.

²²⁶ Osmer, p. 37.

²²⁷ Roy McCloughry, *The Enabled Life: Christianity in a Disabling World* (London: SPCK, 2013), p. 19.

²²⁸ This is the one year empirical research module that forms part of this DThMin programme.

attending to others in their particularity.’²²⁹ The research question that the study was designed to answer was: How do adult Seventh-day Adventists with physical disabilities experience church?

1. Designing a Research Project

According to the educational psychologist John Creswell, there are three component parts that need to be thought through when planning an empirical study. ‘Researchers need to think through the philosophical worldview assumptions that they bring to the study, the research design that is related to this worldview, and the specific methods and procedures of research that translate the approach into practice.’²³⁰

1.1 Worldview

Creswell defines worldview as ‘a basic set of beliefs that guide action’, thus seeing it ‘as a general philosophical orientation about the world and the nature of research that a researcher brings to a study’.²³¹ The four main worldviews that seem to be acknowledged in scholarship are: postpositivism, constructivism, transformativism, and pragmatism.²³²

Postpositivism is based on the scientific method and thus builds on the assumptions of quantitative research. This is where a theory is tested by the collection of objective data, through careful observation and measurement, then revised according to the findings. Constructivism is the usual approach to qualitative research and builds on the idea that individuals construct subjective understandings of their experiences. Thus, the researcher seeks to understand those meanings while acknowledging their own subjectivity in interpreting the data. The transformative worldview seeks to combine research inquiry with political change and is mostly employed to challenge agendas that marginalise social groups such as women, ethnic minorities, or people with disabilities. Pragmatism is the idea behind the mixed method approach to research that combines both quantitative and qualitative

²²⁹ Osmer, p. 39.

²³⁰ John W. Creswell, *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*, 4th ed (Thousand Oaks, CA: SAGE Publications, 2014), p. 5.

²³¹ Creswell, p. 6.

²³² Creswell, pp. 6–11.

assumptions. It focuses more on the problem and uses whatever approach is necessary to understand the problem.

Based on these four descriptions, I decided that the best way to answer my empirical research question would be to build the enquiry on a constructivist epistemology, thus situating it as a qualitative study.

1.2 Research design

Building on from the worldview, the research design that was chosen to give direction to the procedures that were to be used in this enquiry was that of hermeneutic phenomenology.

1.2.A Phenomenology

Phenomenology is a philosophy that seeks to explain how we construct meaning out of our experiences.²³³ It involves the study of phenomena as based on Kant's distinction between *phenomena* and *noumena*.²³⁴ *Noumena* are the things themselves whereas *phenomena* describes our experience of those things. As a philosophy, phenomenology is primarily attributed to E. Husserl (1859-1938), and he introduced several key ideas that are important for understanding phenomenology. We shall consider two of them, namely, the 'life-world' and 'bracketing'.

The concept of the 'life-world' (*Lebenswelt*)²³⁵ describes the idea that our everyday experiences come to us before we reflect on them critically, so they are often taken for granted and go unnoticed.²³⁶ Phenomenological enquiry seeks to understand these lived experiences by attempting to get people to describe their experience and not merely their reflection on the experience.

If we add to this Max van Manen's proposal that phenomenology is a study of essences, in other words what makes a thing what it is and without which it would cease to be what it

²³³ Swinton and Mowat, p. 106.

²³⁴ Marlene Zichi Cohen, David L. Kahn, and Richard H. Steeves, *Hermeneutic Phenomenological Research: A Practical Guide for Nurse Researchers*, Methods in Nursing Research, v. 2 (California: Sage Publications, 2000), p. 3.

²³⁵ Cohen, Kahn, and Steeves, p. 7.

²³⁶ Cohen, Kahn, and Steeves, p. 8.

is,²³⁷ then we can conclude that phenomenology seeks to get at the essence of a person's lived experience. Thus, for example, in order for us to have a meaningful conversation about trees this would imply that there is a common understanding of trees as a phenomenon. This infers that there is a crucial meaning we all are familiar with in order to have a discussion about trees, even though we may not be directly conscious of that crucial meaning. In the case of disability, our discussions are not simply about a definition of the word, which in itself is a very difficult enterprise,²³⁸ but we assume and make use of a shared familiarity with the world in which disability is lived. This shared familiarity is what Alfred Schutz would call a 'stock of knowledge'.

Schutz took Husserl's ideas and related them to sociology,²³⁹ and by so doing he observed that an individual's approach to the life-world is coloured by a 'stock of knowledge' that is made of common-sense frameworks and categories that have a social origin.²⁴⁰ When these ideas and values are applied to experience they make experience meaningful. Stocks of knowledge help create a familiar world partly due to 'typifications', i.e. general categories that are used to describe and explain experience, thus making occurrences identifiable as belonging to a particular category or area.²⁴¹

Translated into my study, this meant that I was seeking to identify the 'typifications' that would emerge from the research participants in the area of disability. Thus, for example, I tried to discover the 'typifications' used by the participants to describe how they experienced being included in church life. Expressing how they encountered others in this way would give a window into the 'life-world' of disability in the Adventist community.

In addition to this, van Manen points out four themes, which he calls 'existentials' which can give helpful guidance for reflection in the research process because they are said to be common to all 'life-worlds'.²⁴² They are: spatiality, which has to do with lived space;

²³⁷ Max van Manen, *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy* (Ontario: SUNY Press, 1990), p. 10.

²³⁸ See chapter 3 above.

²³⁹ Louis Cohen, Lawrence Manion, and Keith Morrison, *Research Methods in Education*, 7 edition (London: Routledge, 2011), p. 18.

²⁴⁰ Norman K. Denzin and Yvonna S. Lincoln, *Strategies of Qualitative Inquiry* (Thousand Oaks, CA: Sage Publications, 1998), p. 139.

²⁴¹ Denzin and Lincoln, p. 139.

²⁴² van Manen, p. 101.

corporeality, encompassing lived body; temporality, dealing with lived time; and 'relationality' or communality, which has to do with lived human relation. Corporeality and communality were of particular importance in this study. The empirical research could therefore be said to be an investigation of people with physical disabilities, i.e. who use help aids as part of their corporeality, and how they experience the existential of relationality in a church context.

A second idea from Husserl is that of 'bracketing'.²⁴³ This is used to describe the setting aside of all assumptions, prejudices and presuppositions by the researcher while in the process of investigating a phenomenon. Schutz also noted that our use of language and 'typifications' makes us assume that others experience the world fundamentally as we do, thus enabling us to understand one another in our interactions in the world.²⁴⁴ Since we take our subjectivity for granted this means that researchers need to be aware of their presuppositions.

This concept of bracketing has garnered much criticism because to completely bracket out one's own preconceptions in order to understand another's experience is surely an impossible task. Nevertheless, it does identify the need for reflective thinking and an awareness of putting one's own interpretation on the descriptions of others.²⁴⁵

1.2.B Hermeneutics

Given that complete bracketing is not possible, we need to allow for some interpretation while seeking to understand experiences. This is where hermeneutics comes in. Since we are interpretive beings that are constantly attempting to make sense of our world, it could be argued that hermeneutics is not merely something we do but rather something we are. Hence some refer to it as the 'general science of interpretation'.²⁴⁶

Descartes is credited with having brought about a major change in thinking, from the medieval reliance on the dominion of texts to the modern supremacy of reason.²⁴⁷ He

²⁴³ Also called *epoché* by Husserl, see Cohen, Manion and Morrison, p. 18.

²⁴⁴ Denzin and Lincoln, p. 140.

²⁴⁵ This will be further explored in the section on reflexivity below.

²⁴⁶ Swinton and Mowat, p. 107.

²⁴⁷ Chris Lawn, *Gadamer: A Guide for the Perplexed*, The Guides for the Perplexed Series (London: Continuum, 2006), p. 31.

applied the scientific method to philosophical thought. Thus for example, the ‘cogito’ argument (I think therefore I am), illustrates his assumption that true knowledge is something internal to the individual knowing subject.²⁴⁸ The resulting scientific rationality put uncritical confidence in the ability of method to build self-validating truths.²⁴⁹

Friedrich Schleiermacher (1768-1834) is referred to as ‘the father of modern hermeneutics’ because of his insistence on the need for a philosophical approach to interpretation, thus making understanding an art in its own right.²⁵⁰ He attended to the linguistic nature of all understanding, emphasizing both its objective or grammatical aspect and its subjective or technical aspect. For Schleiermacher both of these aspects were of equal importance in understanding any text. Thus, he laid the groundwork for a deeper application of the hermeneutical circle, particularly how we understand the overall sense of a text from its parts, which themselves come from attending to the linguistic devices in the text, and how we grasp a text’s sense from comparing it to similar texts.²⁵¹ ‘Thus for Schleiermacher, hermeneutics aims at understanding the sense of a text rather than the context which produced it, though knowledge of the circumstances of a text’s production may prove to be helpful.’²⁵²

Hans-Georg Gadamer questioned modernity’s reliance on method and disagreed with its attempt to break with tradition and discredit the past, because our present is built on the past. We are always a part of tradition so it is part of our social life and not accessible by mere rational investigation.²⁵³

Gadamer believed that method always necessitates limitations. This is because the questions that arise from a given method will only generate the limited knowledge that those particular questions ask. So method is always limiting. Hence, Gadamer highlighted the need for us to be aware that we are rooted in our history and to reflect on how this affects our interpretation of the world.²⁵⁴ Having an awareness of our historical

²⁴⁸ Lawn, p. 33.

²⁴⁹ Lawn, p. 34.

²⁵⁰ Werner G. Jeanrond, *Theological Hermeneutics: Development and Significance* (London: SCM Press, 1994), p. 45.

²⁵¹ Jeanrond, p. 47.

²⁵² Jeanrond, p. 48.

²⁵³ Lawn, p. 36.

²⁵⁴ Hans-Georg Gadamer, *Truth and Method*, 2nd, rev. ed edn (London: Continuum, 2004), p. 278.

situatedness was what led Gadamer to an understanding of prejudice. 'To try to escape from one's own concepts in interpretation is not only impossible but manifestly absurd. To interpret means precisely to bring one's own preconceptions into play so that the text's meaning can really be made to speak for us.'²⁵⁵ Thus, he was opposed to Husserl's idea of bracketing.

According to Gadamer, the job of researchers is not to bracket out their prejudices but to fuse their horizons with the horizons of the research participants. He defines horizon as 'the range of vision that includes everything that can be seen from a particular vantage point'.²⁵⁶ The fusing of horizons sets up an important dialectical process like that of the hermeneutical circle where 'The movement of understanding is constantly from the whole to the part and back to the whole.'²⁵⁷

Given Gadamer's perspective, my research could be viewed as more of a dialogue with, rather than an investigation of, physical disability, which is quite a useful distinction. However, while I would agree that it is impossible to totally bracket out one's presuppositions, it is nevertheless important to do so to some degree. Without this, would not qualitative research merely be an exercise in describing ourselves?

This discussion of methodology highlights the tensions that arise when attempting to combine both hermeneutics and phenomenology.²⁵⁸ Yet it is still considered to be a valid pursuit as it combines both descriptive and interpretive features, both of which were integral components for the design of my empirical research project.

1.3 Research process

Creswell's third component of the research design is to look at the methods and procedures that translate the approach into practice. This will cover descriptions of the sample, the ethical considerations and how the data was collected, as well as issues of reflexivity and validity.

²⁵⁵ Gadamer, p. 398.

²⁵⁶ Gadamer, p. 301.

²⁵⁷ Gadamer, p. 291.

²⁵⁸ Swinton and Mowat, pp. 108–9.

1.3.A Research sample

I decided to limit my research sample to people with physical disabilities because I wanted to test a basic assumption, that the vast majority of SDA church members who could be labelled 'temporary non-disabled' often view physical disability with a negative physiognomy.²⁵⁹ In other words, they make assumptions about a person's character and ability based on their physical characteristics, which in turn will be reflected in how those people will experience church.

As mentioned earlier, my main research question was: How do adult Seventh-day Adventists with physical disabilities experience church? I intentionally excluded the hearing impaired, mainly because the deaf community do not identify themselves as disabled but rather as a minority group with its own culture and language.²⁶⁰

The sample group was made up of 12 people, 8 females and 4 males. From a gender perspective this is obviously quite imbalanced. While there is some discussion among authors as to whether the experience of disability is more limiting for women than for men,²⁶¹ it was not my intention to explore the experience of gender on disability, so the resulting female bias was unintentional. However, in enquiring about gender statistics from the Executive Secretary of the British Union Conference,²⁶² I was informed that here in the UK the ratio is two females for every male in the SDA Church. Thus, my sample turned out to be a true reflection of the gender profile of the church here in Britain.

Three of the participants were blind and were dependent on the use of either a probing stick or a guide dog to navigate in their environment. Five participants were wheelchair dependent and the remaining four needed some other types of assistance such as crutches or walking sticks. Common to all was the dependence on some form of mobility aid, which would make their disability visible to an onlooker.

²⁵⁹ Mikeal Carl Parsons, *Body and Character in Luke and Acts: The Subversion of Physiognomy in Early Christianity* (Grand Rapids, Mich: Baker Academic, 2006).

²⁶⁰ Wayne Morris, p. 4.

²⁶¹ See for example, Creamer, *Disability and Christian Theology*, pp. 16–18.

²⁶² The Seventh-day Adventist church, with a membership of over 17 million worldwide, operates with a four-layered structure consisting of: General Conference (split into 13 Divisions worldwide), Union (usually following national boundaries), Conference or Mission (subdivisions of Unions), Local Church Congregation. See General Conference of Seventh-Day Adventists, *Seventh-Day Adventist Church Manual*. (Hagerstown, MD: Secretariat, General Conference of Seventh-day Adventists, 2016), pp. 27–28.

The age range was from 22-75 years of age, and the underlying conditions varied from congenital conditions such as spina bifida, to late onset conditions such as osteoarthritis. All the participants were baptised members of the SDA church.

1.3.B Ethical considerations

Any research that involves human participants requires ethical approval, so before contacting any of the research participants I applied for low-risk ethical approval, which was granted by the College Ethics Review Committee.²⁶³ Each participant was assured that their data would be safely stored and their anonymity maintained throughout. They each signed the consent form²⁶⁴ indicating their understanding of the project and willingness to participate in the research.

Low-risk ethical approval was appropriate for this study because, even though discussing faith and church experience in relation to disability could potentially be emotionally challenging, I hoped that any emotional consequences would be positive. In fact, judging by their comments at the end of each interview, it seems that having an opportunity to tell their stories did prove to be quite cathartic for the participants.²⁶⁵ Nevertheless, I offered the contact information for ASNA²⁶⁶ to each participant in case they felt the need to talk more about living with their disability at some point in the future.

The question schedule for the interviews was first piloted on a couple of able-bodied colleagues who gave me feedback regarding the questions. I realise that not piloting the questions on persons with physical disabilities was less than ideal. However, I did this because of my fear that I would need every participant I could find in order to have a large enough sample group. If I were to repeat this study I would definitely pilot the questions with a couple of people with disabilities first.

The main critique from my colleagues was that the questions were more geared towards information gathering rather than descriptive of experiences. This enabled me to adjust the questions and arrive at the schedule that was approved by the ethics committee and that is

²⁶³ Reference KCL/14/15-86.

²⁶⁴ See Appendix B.

²⁶⁵ Treloar, 'Spiritual Beliefs, Response to Disability, and the Church -Part 1', p. 25.

²⁶⁶ Adventist Special Needs Association, a registered charity that works to raise awareness and promote inclusion and involvement of people with special needs in the Adventist church. See www.asna.info.

shown in Appendix A. The aim was to have a format for the interview that was somewhat unstructured in order to give the participants the opportunity to speak freely about their experiences, while at the same time having a sense of direction. Hence the interviews were of a semi-structured nature.²⁶⁷

1.3.C Data collection

Each interview was voice recorded and later transcribed. Eight of the interviews were done face to face, either at the participant's home or at their local church, with the remaining four being done via Skype.²⁶⁸ The recordings were kept on password-locked computer files and in a locked cabinet. After transcription these audio files were deleted. I also made notes after each interview that endeavoured to capture the mood and feeling of the encounter. The notes included a general description of how I felt the interview went, any significant occurrences during the interview, and my general impression about how they seem to have experienced church. These notes were very useful in recalling the tone and feelings that each participant conveyed.

1.3.D Reflexivity

As stated in the introduction, my interest in studying disability has arisen because of my experience as the father of someone with a physical disability. Although this can be a positive catalyst for doing this research, it also means that I have come to it with a certain research lens which needs to be made as explicit as possible.²⁶⁹ This act of presenting the features of the researcher's lens involves both epistemological and personal reflexivity.²⁷⁰

Epistemological reflexivity involves questions about the worldview, choice of research design and the research question.²⁷¹ My constructivist worldview made this a qualitative research, whereas a quantitative survey of able-bodied attitudes could have added another voice. Research questions define and limit what can be found in a study. In this case my

²⁶⁷ Cohen, Kahn, and Steeves, pp. 59–64.

²⁶⁸ I would say that Skype interviews are less than ideal. Not only do they make it well-nigh impossible to read body language, but they are also very vulnerable to technological glitches that interrupt the flow of the conversation. Thankfully my four Skype interviewees all seemed eager to participate and did not seem unduly put out by breaks in the communication.

²⁶⁹ Robert K. Yin, *Qualitative Research from Start to Finish*, Second edition (New York London: The Guilford Press, 2016), p. 286.

²⁷⁰ Swinton and Mowat, pp. 59–60.

²⁷¹ Swinton and Mowat, p. 60.

research question limits the finding to problematizing the Adventist emphasis on health, and assuming oppressive attitudes towards people with disabilities in the church.

Connected to this, the question schedule can be said to have constructed the data and findings to equate church involvement with satisfaction, which of course is a very narrow measurement.

From a personal reflexivity perspective, my social identity as being a middle-aged black male pastor could have potentially affected my interaction with the interviewees. In declaring my role as a pastor in the SDA church to the participants, who were all members of the church, this could have affected the findings because of the power imbalance this sets up.²⁷² The interviewees could have been giving me the answers they thought I wanted to hear as a representative of the church system. Conversely, they could have been using this as an opportunity to complain about negative experiences to a person of influence rather than reflecting on their lived experience with a researcher.

Another aspect of the power imbalance could be found in the fact that as a male researcher I was interviewing females. For example, this could potentially have impacted the data that was generated from black females who, from my cultural understanding, would tend to display more deference to a black senior pastor like myself. Also, being black could have been interpreted as me having additional empathy in the minds of black interviewees, which again could have coloured the information that was shared.

The major potential bias in this study was that of me having the experiences of my son in mind when listening to and seeking to understand the experiences of the interviewees. I came to this study to investigate the dynamics of negative physiognomy towards people with physical disabilities because that had been a decisive element in his refusal to visit other churches with me. This could possibly have conditioned me to be listening for evidence to support my preconceived idea of people with disabilities facing predominantly negative encounters, rather than being open to more positive experiences.

Furthermore, my motivation in wanting to give a voice to this marginalized group of people led to the discovery that I was one of the first Adventist researchers to do so. As a result, I

²⁷² Swinton and Mowat, pp. 64–65.

became increasingly aware of the temptation to present the findings in as negative a light as possible in order to have maximum impact and effect.

Having declared these elements of my research lens, we must now turn to issues of validity to see how it is possible to mitigate these problems.

1.3.E Validity

There seems to be no consensus on the question of validity in qualitative research.²⁷³

Nevertheless, I found it beneficial to make use of some of the strategies listed by Creswell²⁷⁴ to assess the accuracy of my findings. Here I will mention clarification of bias, discrepant information and member checking.

As mentioned in the reflexivity discussion, I realise that this research was of personal interest to me because of my son's disability and that this could introduce a certain bias to the way the data was interpreted. Throughout the whole process I kept reflecting on the fact that I am a 'co-creator of the mode and content of the encounter'.²⁷⁵ Writing field notes which included my reflections after each interview was a way of constantly engaging in a self-reflective discipline in order to diminish this bias.

For example, after the second interview part of my notes read as follows,

It was in one sense difficult to ask her my questions because she talked about her own experience as she wished. But then this is the object of hermeneutic phenomenological research. I suppose I would be more comfortable doing a structured interview rather than semi-structured. I need to be better at listening to the cues that come from the people themselves.

Thankfully this came at the beginning of the interviewing process. The reflective process of writing field notes helped me to identify areas of personal weakness as a researcher. For example, I understood in practice why Husserl would say that researchers need to bracket out their own prejudices and presuppositions. On reflection, I realised that I was in danger of trying to read my son's experiences into those of my research participants and that I had

²⁷³ Swinton and Mowat, p. 121.

²⁷⁴ Creswell, pp. 201–2.

²⁷⁵ Swinton and Mowat, p. 61.

a tendency to look for information rather than listen to people's experiences. This reflective process eventually enabled me to become more relaxed in following the direction of the interviewees and in probing their answers.

The inclusion of discrepant information is important because it indicates an awareness of the danger of interpreting the findings using ideological glasses.²⁷⁶ My question schedule²⁷⁷ shows my assumption that church involvement is the main indicator of inclusion. However, the experience of some of the interviewees showed that this was not necessarily true. Also, even though a number of the participants seemed to have had negative experiences, the majority were actually positive and these were also reflected in the findings.

Another strategy that I used in an effort to ensure credibility was member checking. After arriving at my thematic categories I phoned the candidates to tell them my summary and ask if this would be a correct reflection of their church experience. Their additional ideas and comments were noted and used in the final analysis.

2. Data Analysis and Interpretation

The foregoing process resulted in the production of a text of which it could be said that the main authors were the participants and I was a co-author.²⁷⁸ This text formed the data which was to be analysed and from which a number of themes were identified. However, before turning our attention to the process of analysis and interpretation, we will briefly consider some of the ideas involved in the concept of generalizability.

2.1 Generalizability

Because qualitative research is particular in nature it can be argued that the data collected from qualitative studies would make it very difficult to make any generalized applications to

²⁷⁶ Jeanrond, p. 7.

²⁷⁷ See Appendix A.

²⁷⁸ Anders Lindseth and Astrid Norberg, 'A Phenomenological Hermeneutical Method for Researching Lived Experience', *Scandinavian Journal of Caring*, 18.2 (2004), 145–53 (p. 149).

broader contexts.²⁷⁹ A person's experience is unique to them and thus unrepeatable. Yet qualitative research findings can be said to produce a certain amount of identification and resonance with people who may find themselves in similar situations,²⁸⁰ thus showing the potential for transferring findings to other contexts. The scepticism towards generalizability can be attributed to the idea of statistical generalization,²⁸¹ which describes the process of generalizing from a representative sample to a general population. The main problem with statistical generalization is the difficulty of including all the possible variables that would make the sample truly representative.

On the other hand, it is possible to make logical rather than statistical connections and this is known as analytic generalization,²⁸² or theoretical generalization.²⁸³ This involves a two-step process of firstly claiming that a study will inform a particular set of concepts, constructs or events, and secondly, applying the same concepts or constructs to link other similar circumstances.²⁸⁴ Even though SDA churches come in many shapes and sizes and forms around the world, I believe that the culture of efficiency that permeates our gatherings, together with the long standing heritage of our health focus, produces a general Adventist social setting that can be unwelcoming to people with disabilities. Thus, the themes that have been identified below can be said to have the theoretical potential to inform more than the individual interviewee's situation.

2.2 The process of data analysis and interpretation

The process I used to analyse and interpret the data followed the three steps outlined by Cohen, Kahn and Steeves,²⁸⁵ which are: immersion, reduction and labelling themes.

For me, immersing myself in the data began while conducting the interviews, but even more so when I was transcribing them. Having to listen carefully to everything that was said not only helped me to gain a general overview of each interview, but it also gave a more in-

²⁷⁹ Michael Quinn Patton, *Qualitative Research & Evaluation Methods: Integrating Theory and Practice*, Fourth edition (Thousand Oaks, California: SAGE Publications, Inc, 2015), p. 710.

²⁸⁰ Swinton and Mowat, p. 47.

²⁸¹ Yin, p. 104.

²⁸² Cohen, Manion, and Morrison, p. 294.

²⁸³ Swinton and Mowat, p. 48.

²⁸⁴ Yin, p. 105.

²⁸⁵ Cohen, Kahn, and Steeves, pp. 76–82.

depth feel for what was being expressed. After all the interviews were transcribed, they were then collated in a folder and read through in their entirety several times. This enabled me to begin formulating some initial interpretations of the data and allowed me to make a note of the general themes that seemed to be emerging.

The editing work of reduction was done by colour coding the answers that were pertinent to each question. This process helped to eliminate digressions from the topic and personal verbal tics, leaving the relevant materials for comparison. I also organised all the answers to the same question together to see if they brought out similar themes.

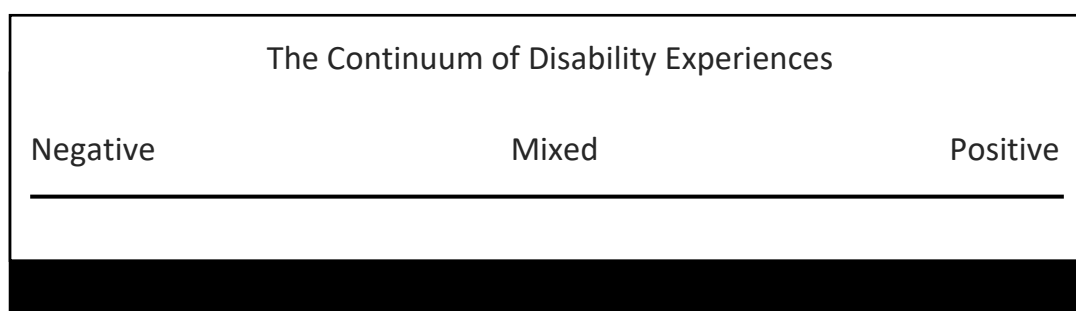
Thematic labels were found by carefully reading each interview and looking in particular for experience descriptions that were accompanied by feelings. These were highlighted and a summary title or idea was noted in the margin. For example, in probing how she experiences her disability in everyday living one interviewee answered, "Not able to doing things for myself, to depend on other people, yeah. It's just like, it's something I always do for myself and I don't like to ask people to do things for me."

I noted 'loss of independence' in the margin next to this highlight. Each summary idea was then collated in a list that made them easier to reflect upon. From these ideas some general categories were arrived at, and then the original transcripts were referred to again to find appropriate illustrative quotes.

2.3 Research findings

As can be expected, there is no singular experience of being a member of the SDA church living with a disability. It is more accurate to say that there is a continuum of experiences that Adventist adults with physical disabilities describe as typical. (See Figure 1). These varied experiences range from discrimination and social exclusion at one end of the spectrum, to total involvement and a real sense of belonging at the other. We will work our way from the negative to the positive.

Figure 1



2.3.A Negative experiences

Of the twelve participants, three of them described their experience as being totally negative. We will call them participants A, B and C. Participant A described her disability as being late onset. She had been very active in church for many years before the onset of a very debilitating condition which also resulted in the loss of her job. Several times she described how important being an active member in church was for her. For example, 'Everything for me is church.' In fact, this could be said about all the participants. Being part of a church family is hugely significant in the life of an Adventist Christian, which is the reason why inclusion in church life is so deeply important and lack of care is so deeply disturbing. Three major experiences on the negative end of the spectrum that will be highlighted are: insignificance, discrimination and stereotyping.

Insignificance

Insignificance is used to describe the experience of feeling that as an individual you are not regarded as an important member in the life of the church, that you are of so little value to the community that if you are not present you will not be missed. Participant A described how undervalued she felt with the following example.

I asked them one time to get a raised toilet seat, and they said it's not their responsibility, it's not their church, it's somebody else's church they're renting. A raised toilet seat that costs £15! The only reason why I don't take mine is that it's too much to carry. I already got the wheelchair. Sometimes I have to carry the

frame with me. Sometimes I have to carry my seat with me. That's the only reason I don't take it with me... In terms of like putting out themselves to, um, incorporate me in the planning, um, I can say that doesn't happen. I don't see the fruit of it so I can say it doesn't happen.

Later in the interview she described the significance of ignorance on the part of her fellow church members.

That's where they've failed, cos nobody wants to take the time. They ask me the same question every time they see me, the same question. 'Oh, how come you said you were sick, and you're walking, you're using crutches?' Or, 'How come last week you were on crutches and now you're in a wheelchair?' And I would say the same thing over and over again. I write them down, I take a leaflet, I put the names down. I said, 'All you have to do is just get the meaning. You don't need to research nothing else. Just get the meaning and once you get the meaning you will get an idea of what is happening.'

Thus, a reluctance to invest finances to accommodate her needs and a disinterest in investing some time to gain a proper understanding of her condition left Participant A feeling that she was insignificant to the church. Participant B echoed a similar feeling when he said 'I think it would have been nice if they could have said, you know, "Can you give us guidance on these issues?" rather than resistance.'

This experience of insignificance, where one is undervalued and seen as a liability rather than an asset, was common to more than these three participants on the negative end of the spectrum. However, what seemed to make their experience so deleterious was the combination of this with other experiences such as direct discrimination and negative stereotyping.

Discrimination

Participant B described his condition as congenital and progressive with a gradual worsening of symptoms. Thus, he became a member of the SDA church with his physical impairments. He summarised his experience thus,

I have to say, and forgive me, um, you know if, if this comes across in a somewhat hostile manner, but I felt this at church, um, and also as, as a person who's been involved in the disabled people's movement for a number of decades, since the 80's. The amount of discrimination I have found at church is probably greater than any discrimination I've found anywhere else. I'm talking specifically about my church. And I have to say what I, um, find more surprising about that is a considerable amount of that has been from, um, black church people, and that is surprising.

He went on to explain that he had expected greater sympathy from black church members because he thought they would have understood what it is like to be discriminated against for being a minority. Unfortunately, his church experience was one of meeting continual resistance to suggestions of change or adaptation to be able to meet his needs. For example, he was elected as the communications officer for the church which meant that he would be a member of the church board.²⁸⁶ The following is his recollection of what made the experience so challenging:

I was adamant that I should be permitted to have my assistant with me even though they weren't a board member, to assist me with papers and hand movement and, you know, general comfort drinks and things. And there was a great deal of opposition to this and in the end, I showed them an article by Lady Jane Campbell who's a friend of mine with the same impairment, who sits in the House of Lords, who is allowed to have her assistant with her on various committee meetings. And you know I said, 'Look, surely if a Lord in effect can have, is our business so sensitive?' And I said, 'I have absolutely no objection with any confidential item for my personal assistant to withdraw from the meeting for the duration of that item.' And I think it was, well I'm sure it was, basically through the persuasion of the pastor that I was allowed in. But I have to say, the experience was not always a comfortable one, and I felt the way in which I was spoken to at times, it was not the way in which a 58-year-old able bodied person would be spoken to or treated.

²⁸⁶ This is the leadership team which steers all the affairs of a local SDA church.

The cumulative effect of this experience of constant resistance and direct discrimination left him feeling like an inconvenience. 'Whether intentional or not, you feel you're burdensome. And I think some of that was made to feel intentional.'

Participant C, whose disability came about as the result of an accident, experienced being completely ignored and marginalised.

I'm feeling gutted. Just, I wanna do, like I wanna be in the praise team. I wanna be able to go up to read a scripture reading. I wanna be on the platform, but I can't be on the platform because the way how they did the altar and stuff I won't be able to get up there, because it doesn't have any rails or anything for me to hold on to. Cause I hold my cane in my right hand. If the rail was on the left or right side I would be able to get up, but there's none. And there's stairs as well and I'm not good with stairs... It's not good because I'm not included in the church. I like to look after other people, so like if someone comes in a wheelchair I'm gonna be like, "Ok, you guys need to move that bench for that person to fit in." That's the kind of person I am. So for me to be going through this and they're not supportive and stuff like that, it's just tearing me up.

From these comments it appears that being on the praise team was especially significant for her church life experience. However, she was left with a feeling of being discriminated against because she had been an active member of the team before her accident, but experienced a clear change in attitude towards her involvement in church afterwards.

This may give the impression that there was a lack of self-understanding on the part of the participants in expecting more inclusion than their impairments allow. However, Participant A expressed that she was acutely aware that her impairments mean that she is more high maintenance. Describing herself in the third person she said, 'You've got the wheelchair, you've got getting her dressed, um, you've got getting her meals together, you've got to make sure when you've done that then you've got the cleaning up. It's not just a five-minute thing anymore.' Helping her after church would require the following:

You'll have to get me in the house, you'll have to change me, clean me up, get me dressed for bed, give me something to eat for the night, and I think that's where a lot of the sparseness comes about.

The 'sparseness' was her way of describing how little help she gets from church members.

One time they tried to arrange, um, housekeeping, um, they had a million meetings... The reason I asked was so that since I am home and I can't go up there I would still feel connected to the family because they're coming here and I'm seeing them at least once a week... It's not, I don't want a debate over washing my clothes. That can be sorted. I can pay one of the carers to do it. They will do it easily.

Feeling connected to the church family while being housebound was obviously very important, but this was unfortunately not recognised by her local church and thus an opportunity to underscore her significance was lost.

Stereotyping

A third element that added to a largely negative church experience was that of encountering stereotypical attitudes towards disability. This is where disability is viewed as something negative and treated as a problem of the individual.

One example from Participant A illustrates the negative attitude that quite clearly left her feeling undervalued for simply having an impairment. Three months after falling ill, during which time she was learning to negotiate the use of crutches, her church was going to have a musical program which she had not been told about.

The funny thing about that too is that from since I've been in that church I think for the first eight years I sang every Sabbath... There were people who were invited to tell their story, so what it was is that you were sick and whatever, and then you, um, talk about your progress, or your healing or whatever is keeping you, comforting you and that kind of stuff... And, um, my adopted daughter, well they adopted me as, these five girls they adopted me as mum since I've been here, and she was angry... She was angry because she wanted to know why. She went to ask them, 'Well why was mum not invited to take part in the programme?' And she was told, 'Well we

didn't ask her because she's disabled, she can't walk, so we didn't ask her to sing.'
...There's no need to ask anything else. I don't use my feet to sing. I don't use my hands to sing. As a matter of fact, the strongest part of my body is my mouth, and that's the only thing I have got.'

In recounting this episode, the disappointment of her experience was still very palpable even though it had occurred several years earlier. Participant B's description of his experience at a particularly memorable business meeting,²⁸⁷ also illustrates the effects of enduring stereotyping.

The comment thrown to me at that business meeting was 'What's your problem?' And my response was 'It's not my problem,' you know. And access shouldn't be my problem. You know, the wheelchair, my wheelchair is not a problem it's an enabling tool to me, um, and it's the steps that used to exist at the front door that were the problem. Um, two narrow doors are the problem. It's not my problem, it's what was put there by someone else. And my whole perspective is that if we are to take the gospel forward to everyone, then why does this church, and I suspect probably others, seem to ignore one particular group?

Thus, the combination of feeling that you are insignificant for your church family when you suffer with an impairment, being the recipient of direct discrimination and stereotyping, left some participants with a very negative experience of being a person living with a disability in the SDA church. It is these negative experiences in particular that elicited the liberation wording of my research question. In order to address the restrictive and oppressive attitudes and behaviours described by these research participants liberatory action is needed in the church.

2.3.B Mixed experiences

The middle area of the spectrum could be described as encompassing experiences of being generally accepted and included but punctuated with moments of demoralisation due to insensitivity. Three participants from the research cohort seemed to fall within these

²⁸⁷ This is the constituency meeting for all members of a local SDA church and they usually take place every three months.

boundaries. These will be referred to as participants D, E and F. Participants D and F described their conditions as blindness, whereas Participant E described her impairment as a mobility issue that she was born with resulting in her dependence on the use of crutches.

Ministry inclusion

Participant D became a church member as a mature person and his experience of church started out with merely being in attendance.

At one time I wasn't included at all. I suppose perhaps people didn't think, I don't think it was anything nasty about it, perhaps people didn't think at all, perhaps people didn't consider me... We've all got talents, we've all got different skills, so perhaps people have not given me another thought.

In describing his early church experience he used phrases such as, 'You can feel out of things,' 'Felt on the margin,' and 'You come into church, you go home again.' These express a sense of merely being an attendee rather than an actively contributing member of his church. One could wonder why people continue to attend a church when they feel so marginalised. The answer seems to come from a sense of hope. Participant D went on to describe the advice he was given by the pastor who baptised him.

I think things are better now than they were. Now I'm a deacon, things have improved. I feel more involved than when I first joined... I was baptised in 1998, I was presented with a Bible... I was baptised by a pastor [Named]. He's very good, we're good friends. And he gave me some really good advice, when I got baptised, he said, 'Don't expect it,' he said, 'things will grow on you, the church will grow,' he said. 'Don't expect it all to come at once,' he said. 'Friends for life will grow over the years,' which it has done.

The hope of a growing level of friendship and participation seemed to sustain this participant's commitment to his local church community.

Participant D's initial experience of marginalisation changed to one of excitement and satisfaction due to his involvement in the church. With great enthusiasm and pleasure he said, 'But since I've become a deacon it's brilliant! I'm glad cos I've felt now you're

involved... you feel you're offering something.' This transition was significant because it fostered in him a feeling of worth and usefulness. 'I feel that you're serving the church, you're part of the congregation, not just coming in.' He now describes his current experience in the following way: 'I think people accept me now. I've got many good friends in church... There's a rota and there's about six on it... people bring me to church and take me back and they do it two months at a time.' He constantly referred back to his role as a deacon which obviously has given him an experience of being an important member of his local church community.

This participant was very fortunate because he did not need to push for his participation, but was approached by someone who asked him if he would like to become a deacon. Participants E and F had to be more forceful to be included. Participant E mentioned several times that she had to 'put her foot down' in order to be taken seriously. Eventually her involvement in various church ministries happened after she wrote a couple of books retelling her experience of growing up with her disabilities. She seemed to have to prove her ability before being viewed as resourceful.

Participant F described a similar experience. The following quote describes the lengths she had to go to in order to be noticed and considered for a church office.

So take for example, when I was baptised, then there was a big baptism I think about nineteen of us, the biggest baptism here. And then they start to organise people in departments, you know, to get us settled in. And then I wasn't put anywhere so I went to the elder, I said 'Hold on, everybody is put somewhere, what about me?' and that didn't, no attention was paid so I went to the pastor. So I said 'I need to be settled somewhere also.' Um, they never did really put me anywhere, so when I see that they start to announce different things, prison ministry, then I put my name forward, and I phone the person, I said, um, 'Now what do you need to go into the prison ministry cos I like to deal with people?' I can go out there and talk for England (chuckles), so I know that I feel that I would be effective in the prison ministry. So I went to him I said 'So what do I need?' and I follow it up, so a lot of things is like me following things up. And then one time one of the elder asked me to do some, to do a prayer and did the disability department, the people realise 'Oh she can do

something.’ And then from there I’ve been asked on different occasion to take part in divine hour, do prayer and so on and so forth.

Thus, her involvement initially came about as a result of her own initiative rather than the church seeing her as a resourceful person. Fortunately, after these initial struggles she describes her experience today as much more positive even though there are moments of negativity.

I still experience negative things even although there is disability awareness programs it still not sinking in. You have good people who treats you well. Who just see you as another human being, but you still have people, and sometimes even within the church it, what I would say, wound your soul, you understand? And then you have to go and really go down on your knee and pray for healing, really pray because sometime people open their mouth and they, and I said, ‘Do they think that you don’t have feeling?’

Occasional insensitivity

She went on to describe a particularly memorable incident at her baptism when she had her little son with her. She heard a lady sitting two rows behind her commenting on her blindness and being a mother. She continued to recount the story,

Then my sister said ‘Sorry?’ Now pastor, considering she’s about three, two rows behind the row I am and so those two lots of people would be hearing her, the two set behind her would be hearing her, and she’s saying, ‘How did she manage to find a husband to, for her to have children and I can’t even find.’ Now pastor what was going to come out of my mouth... I turned and my sister said, ‘Shh, you just baptized.’ Yeah, and I sat down.

She also recounted another occasion that she found quite hurtful. She was sitting around a table with some other women talking about husbands and she made a comment. The following excerpt is how she continued the story and commented afterwards.

And then somebody said, ‘Oh but like you, you can’t say anything because you won’t get a husband anyway because if normal people can’t find husband, how are you

going to find husband?’ So those are the things pastor that would really destroy you. And if you’re not a strong person, and a few times, well over the last five years, I get so discouraged that I said I wasn’t coming back. But then again I know God called me, and I got saved right in my own house with the Spirit talking to me, telling me you know, you need to change up your life, so I know that I’m not here for them, and so I keep going. So you know, you can get a lot of negative which can really, the disability in itself is easy comparing to how people see you. And then you’re hoping that because people inside here should have love that you would come into a place and experience that sort of atmosphere, but it’s not always that way. And although I’m sounding negative there are still a lot of positive things that still goes on so I still have to try and balance it.

The balance she speaks of is the reason why she has been placed in the ‘mixed’ section of the continuum of disability experiences. Furthermore, when asked her general impression of being included in the life of the church she said she felt that she was generally included, but socially excluded.

If a social is happening at church, fine. But if they’re having a social as a family that if we should be, then I’m forgotten. Yeah, I’m forgotten... I consider the church as my extension because I don’t have any extended family near me, but time and time again I have to take that back because you know, they will have, even sometime they having lunch, they won’t invite you. Um, they having birthdays they won’t invite you. It’s a strange thing pastor, because you sit down and you think the people that should look at and try to give a bit extra, they are the one that they don’t, they more look at people who they know. If I invite them then will get an invite back. If I do this for them then I’ll get it back and it’s a tit-for-tat thing.

It is quite safe to say that Participant F’s church experience, as summed up in her own words, has been somewhat ‘bitter-sweet.’

Thus, from these three participants we can sum up their experiences as a mixture of both good and bad encounters. Inclusion in the life of the church is perhaps the key component in having a positive and fulfilling church experience, even if this has to be fought for.

Episodes of unguarded negative comments and derogatory attitudes towards disability are obviously deflating and leave a negative colouring on church experience. Hence the mixed section of the continuum can perhaps be portrayed like a ship rocking from side to side on an even keel.

2.3.C Positive experiences

It was pleasantly surprising to discover that the majority of the research participants described their experiences in a way that would situate them on the positive end of the continuum. This can be interpreted as indicating that the SDA church is generally doing well in the way it treats members with physical disabilities. From my research group, six of the participants (or 50%) had overwhelmingly positive experiences. Four of the participants were wheelchair dependent, one was dependent on crutches and one was blind. These will be referred to as participants G to M.

Participant G had always been involved with music in the church. She described that she was very happy to be the organist in her local church, and that for her was more than enough involvement. When asked if she ever felt excluded from the church fellowship she replied 'I'm right in the middle of it! I think you'd better get that quite clear.' She described being an active participant in a small group resulting in her having very good friends in the church and giving her a strong sense of belonging.

She expressed a very positive outlook on life and saw problems as challenges to be creatively resolved rather than obstacles to be complained about. For example, the place where her church meets is on the first floor of a building and she is unable to climb up stairs. However, she has people who carry her up.

[Named] carries me up those stairs every Sabbath, and one or two others have got the technique of getting me up those stairs, which I am so grateful for. You know, there's always a fringe benefit of being disabled! I get manhandled by the nice, strong, you know, good-looking. I pick out the most good-looking, strong handsome gent I can find! (laughs)²⁸⁸

²⁸⁸ This would seem to corroborate the suggestion that being carried into a building may be a more valuable indication of positive church community than having a ramp put in. See Wolfensberger, p. 123.

She went on to explain that she does not make too much out of her limitations and that seems to colour her whole church experience. 'I do what I can do, and people seem to know where I'm at. And they accept it and I accept it and we have a laugh about it, or they say 'How are you now?' and I say 'Oh it's pretty rough you know but oh...' Try to live in the present!' Thus, having the space to be herself and knowing that she is accepted has made her church experience an overwhelmingly positive one.

Participation obviously has a very positive impact on the lived experience of people with physical disabilities in the church. However, there can be a down side to this. Participant H described being very involved in her local church, leading four different ministries! She was very glad to be a central part of her church but she did express the following concern, 'But sometime they put too much of pressure on you to do so much of things.' 'They expect you to do so much and forget that you're ill, yeah.' She seemed to be expressing a kind 'hero pressure' where she is expected to perform beyond what would normally be expected of a person living with certain impairments. This was also expressed by Participant J in the following way:

People's attitudes can be quite frustrating at times, um, when people want to see you as an inspiration and they kind of put that upon you. Um, you know, I feel that particularly in the church community... There's one particular person who always approaches me with "You're alright aren't you?" And I always think that's telling I've got to be ok. I'm not allowed to be anything than ok. And sometimes I'm not ok (laughs). Um, and obviously, people that are closer to me are more accepting of that, but some people want to see me as almost like a conquering hero, managing to cope with everything that's thrown at me, and sometimes I don't.

This perhaps illustrates what some commentators have seen as the pitfall of the Paralympics. One can be left with the question, 'Do I have to be exceptional to be accepted?' Nevertheless, Participant J went on to describe her fellow church members in the following way, 'They really have been amazing.' 'I think, generally speaking, everybody's been fantastic and understanding and been there 100% for me when I've needed them to be.' She described that they were aware of her needs and were more than willing to make adaptations to fit her needs. Also, being the elder of her church meant that she was right at

the heart of everything that happens in her local church fellowship. It was interesting to note her explanation for her heavy involvement. 'I suppose that also is another reason why I do so much because I feel, you know, so grateful.'

Other participants expressed complete satisfaction at their level of inclusion and participation in the life of the church, and the proactive initiative of their church in trying to help them be included and have their needs met. Participant K expressed this in the following way:

They were really good. They would just come and ask, like if I needed anything. And not in a condescending way or anything, just kind of, because obviously I might have a problem and stuff that other people don't, and so they would just ask and yeah, really open. Just sorting the things out, so I could take part if I wanted to, but then if I didn't then that's also fine.

Again, having the space to be as involved as you want went a long way in making his church experience a pleasurable one.

Thus, the positive end of the experience continuum is characterised by the following four occurrences: being included in ministries, being on the receiving end of a proactive willingness to make necessary adaptations to meet accessibility needs, experiencing an acceptance of varying levels of involvement with the caveat that sometimes this can lead to the pressure of performing like a hero, and having personal friends that give a sense of being socially included.

In conclusion, having performed the task of formal priestly listening through an empirical research study, we can diagrammatically summarise the voices of these twelve SDA church members with physical disabilities in the UK in Figure 2.

Figure 2

The Continuum of Disability Experiences		
Negative	Mixed	Positive
Insignificance Discrimination Stereotyping	Ministry inclusion Occasional insensitivity	Ministry inclusion Proactive adaptability Involvement space Belonging

Having discovered this wide range of experiences, we now move on to consider theories that can help to explain why these occurrences may have taken place. This is the object of the interpretive task, to which we will turn in the next chapter.

Chapter 6 – Investigating Theories

(The interpretive task)

The previous chapter disclosed a range of somewhat ambivalent attitudes towards disability that are exhibited in the Adventist church. This chapter will focus on possible explanations for these attitudes by employing insights from the social sciences. While we will naturally concentrate on trying to understand the occurrence of negative features such as insignificance, discrimination, stereotyping and insensitivity, some of the positive responses will also be touched upon.

As suggested above in chapter four, the interpretive task can be seen as a spiritual act of sagely wisdom. Some of the characteristics of Wisdom literature suggested by Osmer are that it seeks to give guidance on how to live life, it reflects on observable patterns of life from which general insights are derived, it helps people to think in order to shape a good character, and based on creationist assumptions it is open to and willing to learn from the observable world.²⁸⁹ Based on these characteristics it will therefore be worthwhile to explore insights from some of the social sciences. This is because they offer a deeper and more rich understanding of the kinds of dynamics that seem to be at play in situations such as those described in the previous chapter.²⁹⁰

In seeking to unpack the complex dynamics that may dictate the attitudes displayed by Adventists towards people with physical disabilities, we will concentrate on sociological, psychological and doctrinal explanations. Sociological explanations are sought because the research describes behaviours that appear to be triggered by social interactions. Psychological explanations are explored in order to try and understand some of the thinking processes that may be at play when disability is confronted. Doctrinal explanations are investigated because, like all Christian communities, Adventists acknowledge the influence that doctrinal beliefs have on the actions of their members.²⁹¹

²⁸⁹ Osmer, pp. 88–93.

²⁹⁰ Swinton and Mowat, p. 96.

²⁹¹ General Conference of Seventh Day Adventist, *Seventh-Day Adventists Believe: A Biblical Exposition of Fundamental Doctrines*, Second (Boise, ID: Pacific Press Publishing Association, 2005), p. viii.

1. Sociological Explanations

Sociological theories can be divided into two broad categories,²⁹² structural or macro perspectives and social action or interpretive perspectives. Structural perspectives focus on how society functions as a whole. For example, Marxism sees society as being economically based and divided into various social classes that tend to be in conflict with each other.²⁹³ Interpretive perspectives, on the other hand, see society as resulting from human interactions, for example social action or symbolic interactionism.

An example of symbolic interactionism would be Erving Goffman's theory of stigma which has had a significant influence on the sociological understanding of minority groups.²⁹⁴ He defined a stigma as 'an attribute that is deeply discrediting'²⁹⁵ and is also socially constructed. Goffman sought to understand what was happening at moments of contact between those designated as normal and those with some form of stigma.²⁹⁶ His underlying idea was that a stigma looms so large in social interactions especially because of its visibility, that it affects an individual's self-perception, leading them to embrace the values of the dominant culture. At the same time, it accounts for the negative reaction of the majority. In the words of Goffman: 'By definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often un-thinkingly, reduce his life chances.'²⁹⁷

Using Goffman's perspective, it could be said that the negative experiences of SDA members in the UK with physical disabilities can be explained by this understanding of them as possessing some form of visible stigma. This, however, would be a very simplistic interpretation. Goffman's work has been critiqued for its focus on the individual and how his or her presence disrupts social interactions while ignoring the role of social

²⁹² Michael Haralambos and Martin Holborn, *Sociology: Themes and Perspectives*, 8. ed (London: Harper Collins, 2013), p. 953.

²⁹³ Ibid.

²⁹⁴ Jeffrey Brune and others, 'Forum Introduction: Reflections on the Fiftieth Anniversary of Erving Goffman's Stigma', *Disability Studies Quarterly*, 34.1 (2014) <<https://doi.org/10.18061/dsq.v34i1.4014>>.

²⁹⁵ Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (London: Penguin, 1963), p. 13.

²⁹⁶ Goffman, p. 23.

²⁹⁷ Goffman, p. 15.

institutions.²⁹⁸ It has also been critiqued for its assumed 'normative' approach and failure to recognise the agency of disabled people.²⁹⁹

More helpful to this interpretive exploration of Adventist experience could be Paul Hunt's contribution in his book entitled *Stigma*. He suggests that the idea of challenge could give a reasonable sociological explanation for the experiences of people with physical disabilities. In this sense he can also be seen as illustrating an interactionist perspective to sociological understanding, where people with disabilities challenge the roles that are expected of them. Hunt proposes the following five ways that people with disabilities offer a challenge to society, by being: unfortunate, useless, different, oppressed and sick. These are usually thought of as passively suffered by them but here he is offering them as an active challenge to society.

1.1 Misfortune

By being 'unfortunate' a person with disabilities challenges the belief that a person's worth depends on how fortunate he or she is, on the goods they own and the social position they have. If confronted with a person who seems very happy and fulfilled with their situation, Hunt suggests that the able-bodied usually tend to deny the reality of the person's adjustment. They are believed to be simply putting a brave face on things. If the disabled show no sign of suffering, then they challenge those whose worth is bound up in their position of fortune. They challenge the assumption that certain 'goods' are imperative for complete human existence.

The experience described by participant C in chapter 5 above as falling under the 'discrimination' subtitle is perhaps a good illustration of this mechanism at work. She had been an active participant in the praise team before her accident and had expected this to continue after her recovery. In her mind, her dependence on a mobility aid did not preclude her from active church participation. However, her experience of being completely ignored and marginalised seemed to suggest that the misfortune of her disability was too great an obstacle to overcome in the minds of her fellow church members.

²⁹⁸ See for example, Brendan Gleeson, *Geographies of Disability* (London: Routledge, 1999), pp. 21–22. Also Eiesland, pp. 60–61.

²⁹⁹ Brune and others.

1.2 Uselessness

Being 'useless' challenges the idea that work and productivity are the most important contributions a person can make. Thomas Reynolds refers to an 'economy of exchange' which is 'a system of reciprocity that regulates interactions in a community.'³⁰⁰ Economies of exchange are said to function using 'body capital' which reflects what a community sees as being of worth and useful. The exchange value is what gives power, especially the power to belong.³⁰¹

While economic productivity is not a main concern of a church community, the idea of productivity can be found in the potential for service by using one's spiritual gifting. The Church Manual, which is the official governance book describing the operation and functions of local SDA churches and their relationship to denominational structures, lists thirty different departments that can be found in a local church.³⁰² Thus it can be said that Adventist church life is very resource intensive. The danger inherent within the community is in projecting the idea that a person's worth is proved by the service that they are able to offer in helping the church run efficiently. The experiences described under 'insignificance' illustrate the challenge of uselessness that the presence of people with disabilities obviously brings to some SDA churches.

1.3 Difference

Being 'different' offers a challenge to the goals and principles of normality. To be challenged by difference perhaps betrays an inability to accept oneself and to allow others to simply be 'other'.

Jenny Morris observes that 'In our society, prejudice is associated with the recognition of difference and an integral part of this is the concept of normality.'³⁰³ She goes on to explain that even though the idea of normality can be seen in various ways, the main problem is that it carries with it the idea of value. That which is not normal is considered to be wrong, undesirable and unwelcome. Therefore, since people with disabilities are physically

³⁰⁰ Reynolds, *Vulnerable Communion*, p. 56.

³⁰¹ Reynolds, *Vulnerable Communion*, p. 58.

³⁰² General Conference of Seventh-Day Adventists, pp. 178–79.

³⁰³ Jenny Morris, p. 15.

different and they have additional needs they are easily regarded as less valuable. Morris suggests that this prejudicial devaluing takes place in the form of hidden assumptions and she offers a long list of examples.³⁰⁴ She goes on to note 'One of the most oppressive features of the prejudice which disabled people experience is the assumption that we want to be other than we are; that is, we want to be normal.'³⁰⁵

It is easy to see how the experiences described above under the 'stereotyping' subtitle are illustrative of the dynamics involved in the challenge of difference. They exemplify Thomas Reynolds observation that 'a community's perception of disability is the inverse projection of its own framework for normalcy.'³⁰⁶

1.4 Oppression

Being 'oppressed' challenges people's inner attitudes. In the words of John Swinton, 'Oppression is perhaps best understood as a power or force that prevents a person from becoming fully human and thus fully reflective of the image of God... To oppress others is to dehumanize them.'³⁰⁷

Paul Abberley argues that oppression has an element of inferiority that is related to an ideology that justifies and perpetuates the position, even though such inferiority and ideology are not natural or inevitable, and there is a beneficiary of this state of affairs.³⁰⁸

The negative experiences described above can all be said to start from a point of assumed inferiority, which, when combined with the ideology of optimum health that is so central in Adventist culture, can easily result in an oppressive environment for people with disabilities. In fact it is this oppression that has prompted the research question for this thesis. In other words, we are exploring what the SDA church can do to authentically proclaim liberty from the oppressive attitudes that result in people with disabilities experiencing insignificance, discrimination, negative stereotyping and insensitivity.

³⁰⁴ Jenny Morris, pp. 17–19.

³⁰⁵ Jenny Morris, p. 27.

³⁰⁶ Reynolds, *Vulnerable Communion*, p. 33.

³⁰⁷ Swinton, *Resurrecting the Person*, p. 17.

³⁰⁸ Abberley, p. 7.

Furthermore, in addressing the topic of oppression Paulo Freire asserts that discovering that one is an oppressor may produce 'considerable anguish' which can lead to a rationalising of guilt 'through paternalistic treatment'.³⁰⁹ Thus for example, the dynamics behind the idea of charitable giving, which makes people with disabilities dependent on the goodwill of others and needing to give gratitude in return, can be said to create a culture of dependency that is in fact oppressive in nature.³¹⁰ Some of participant B's experiences, in particular, seem to illustrate where prejudice takes on subtle and not so subtle forms of forcing the will of the disabled. This can be seen as further evidence of the challenge that oppression can bring.

1.5 Sickness

Being 'sick' challenges the sense of invincibility that is felt by members of a community and forces them to confront their own mortality. One area where sickness particularly challenges the community is mental illness. Greene-McCreight observes that mental illness is the one form of disability that it is still socially accepted to hold prejudice against, even in Christian communities.³¹¹ She attributes this prejudice to fear and ignorance of what mental illness is, and concludes that sick people are not necessarily weak, but rather afflicted.³¹²

Illness can also be challenging either due to lack of acceptance or always assuming healing. Coleman's story illustrates how she tried to keep her mental illness hidden because whenever she told people how she was feeling they never believed her. Her relief came when she eventually met a doctor (the twelfth in four months) who really listened to her and treated her like 'a smart person who was sick.'³¹³ Colwell, on the other hand, questions the assumption that all illness and suffering should be overcome and healed. He shares how accepting that he was ill as a result of a chemical imbalance in his brain, enabled him to begin coping with his condition of clinical depression.³¹⁴

³⁰⁹ Freire, p. 31.

³¹⁰ Jenny Morris, p. 72.

³¹¹ Greene-McCreight, p. 23.

³¹² Greene-McCreight, p. 162.

³¹³ Monica A. Coleman, *Bipolar Faith: A Black Woman's Journey in Depression and Faith* (Minneapolis: Fortress Press, 2016), p. 285.

³¹⁴ John E Colwell, *Why Have You Forsaken Me?: A Personal Reflection on the Experience of Desolation*. (Milton Keynes, 2014).

Thus, it can be said that an interpretive sociological perspective can help the SDA church to realise that the source of its success has the potential to become the cause of its failure towards people with disabilities. As observed by Hunt, 'The quality of the relationship the community has with its least fortunate members is a measure of its own health.'³¹⁵ Thinking in terms of church health, an engagement with sociological theory can be seen to give insight into the varying social dynamics that may have prompted the particularly negative attitudes illustrated by the research findings in the previous chapter. In other words, one conclusion that can be drawn from sociology is that unwelcoming church environments for people with disabilities should be expected in Adventist communities because they are a reflection of the wider society. In order to be communities of genuine liberation particular social dynamics would therefore need to be actively and consciously counteracted.

2. Psychological Explanations

In order to explore possible psychological reasons why SDA church members react the way they do, we will utilise the suggestion of sociologist, Bill Hughes, who offers what he sees as the three major emotions that form the 'building blocks of the emotional infrastructure of ableism'.³¹⁶ They are: fear, pity and disgust.

2.1 Fear

According to Hughes, the emotion of fear in regard to disability is based on a denial of our own frailty and vulnerability. Since modern society likes to portray beautiful and stable bodies as the norm, encounters with bodies that portray otherwise will always be emotionally challenging. The attempt is then made to resolve the challenge by distancing oneself both physically and emotionally from the source of fear.³¹⁷

Hughes goes on to clarify how psychoanalytical ideas have exposed the threat element that is found in fear. This again is based on the notion that the non-disabled like to privilege the ideas of wholeness and independence because they conjure up in the imagination the

³¹⁵ Hunt, p. 10.

³¹⁶ Watson, Roulstone, and Thomas, p. 68.

³¹⁷ Watson, Roulstone, and Thomas, p. 69.

idealistic image of an invulnerable body. However, the presence of a disabled body threatens idealistic and narrow ideas of how bodies should properly conduct themselves in public.³¹⁸ Thus Hughes concludes that the 'fight or flight' reaction that is induced by fear can explain the hiding away of people with disabilities in previous years or even perhaps the rise in disability hate crime.

Robert Wilton suggests that the mechanism of projection can offer further explanation of the fear reaction. He suggests that projection is used by the non-disabled to endow the disabled body with a deficiency. However, this is subverted each time a disabled person fails to fit into their assigned role but instead displays the superiority rather than inferiority of disability. This destabilising of the ordered system of the non-disabled imaginary is said to be fear inducing.³¹⁹

Trying to understand the dynamics of fear can be a complex endeavour especially given the various schools of thought in the field of psychology. However, focusing on the emotion of fear can be a worthwhile avenue to pursue in examining the Adventist experience of disability. The distancing reaction of fear is particularly insightful in explaining, for example, the experience of lack of inclusion as recounted by some of the research participants. In the same way, the mechanism of projection can shed light on some of the discriminatory experiences. Furthermore, this may not only be reserved for negative experiences on the spectrum. As Jenny Morris has pointed out, stories that feature the act of overcoming adversity are seen to be important because they lessen 'the fear that disability holds for non-disabled people'.³²⁰ Thus, even the ministry inclusion experiences that were highlighted on the positive end of the experience spectrum can be susceptible to more subtle expressions of fear.

2.2 Pity

The feeling of pity builds on seeing people with disabilities as unfortunate. It can be summed up in a phrase that, notwithstanding its noble history, can be interpreted as

³¹⁸ Watson, Roulstone, and Thomas, p. 70.

³¹⁹ Robert D. Wilton, 'Locating Physical Disability in Freudian and Lacanian Psychoanalysis: Problems and Prospects', *Social & Cultural Geography*, 4.3 (2003), 369–89 (p. 381) <<https://doi.org/10.1080/14649360309069>>.

³²⁰ Jenny Morris, p. 68.

ambiguous and patronising. It is the idea ‘there but for the grace of God go I.’ Hughes points out that the problem with pity is that it is ‘a hierarchizing emotion’.³²¹ In other words, pity constructs inequality because it carries with it a negative evaluation of its object and results in those possessing it feeling superior to those who are its object. Social model proponents see pity as the number one emotion that non-disabled people seek to show as an appropriate emotional response to disability.

The way in which pity often manifests itself is in charitable giving. This is particularly true in the Christian community where it is seen as a religious duty to give charity to the poor. However, the giving can be seen as a one-way othering of those who are perceived as different. Hughes observes that ‘The charitable attachment to the disabled other is saturated with selfishness because it sustains one’s sense of ontological security and wholeness.’³²² In other words, charitable giving can have a self-congratulatory aspect to it because it confirms the virtue of the giver.

This perhaps explains why those who take a disability rights position endeavour to point out the negative side of pity. They tend to view pity along the same lines as Nietzsche who opposed Christian pity as ‘a multiplier of misery and as a conservator of everything miserable’.³²³ Rather than seeing it as a virtuous Christian ideal, those in the disabled people’s movement view pity as leading to an invalidating of that which is seen as abnormal. This clarifies why some fight against fundraising endeavours such as telethons, because they are said to propagate the ideas inherent in a culture of dependency.³²⁴

For the SDA church this offers a sobering element of self-reflection about the motives behind inclusive practices. Compassion should not be underestimated or demonised. However, the hierarchising nature of pity can perhaps help to clarify the ‘mixed’ category of experiences that were described by some of the research participants. Inclusion that has to be fought for can evince an underlying attitude of pity. The hierarchy that pity sets up in the mind would mean that members with disabilities are usually not regarded as resourceful but

³²¹ Watson, Roulstone, and Thomas, p. 71.

³²² Ibid.

³²³ Friedrich Wilhelm Nietzsche, *Twilight of the Idols: And, The Anti-Christ*, trans. by R. J. Hollingdale, Penguin Classics (London: Penguin Books, 2003), p. 130.

³²⁴ See for example, Jenny Morris, pp. 72–74.

rather a drain on resources. Their eventual inclusion may then initially be conceded to from a position of condescension rather than equality. Hence, the demoralising experiences of insensitivity that seem to punctuate what would appear to be otherwise positive inclusion, could be a demonstration of how an attitude of pity works itself out in an Adventist context.

2.3 Disgust

Disgust is described as a reaction to something that is perceived to be dangerous because it is assumed to have the ability to 'contaminate, infect, pollute by proximity, contact or ingestion'.³²⁵ Hughes points out Sartre's description of the slimy as a classic example of something that disgusts. 'The slimy disgusts us because it invokes what is ambiguous and anomalous,'³²⁶ and people with disabilities can evoke the same feelings because they embody loss of autonomy and control.

Hughes uses the example of saliva to show how the ideal of keeping it out of sight has been socialised in history. Saliva then becomes socially problematic when, for example, it is seen to escape from the mouth through drooling which can be a symptom of an impairment (known medically as ptyalism). The interesting thing is that this is generally accepted in babies but becomes abhorrent in adults. The idea is that it is a stark reminder of our vulnerability to degeneration and decay that we would rather not face up to. Hence his observation that 'Disgust in the presence of disability is a form of cowardice in the face of inevitability and a failure to recognize that mortality is not an enemy but simply the price one pays for life.'³²⁷

This reaction of disgust did not appear to be depicted in this research. It is perhaps typical of an immediate first-time reaction to physical disability that is particularly disfiguring. This did not feature in the sample of participants in this research project. Nevertheless, it could be a possible explanation for some of the strong reactions of discrimination and stereotyping that were described by the participants. If this research had included people with severe learning difficulties one may suspect that the emotion of disgust would have featured more prominently.

³²⁵ Watson, Roulstone, and Thomas, p. 73.

³²⁶ Ibid.

³²⁷ Watson, Roulstone, and Thomas, p. 73.

3. Doctrinal Explanations

Numerous authors point out the hindrance that theological ideas present for people with disabilities to be fully included within the Christian community. For example, Charlton claims that by linking the origin of disability to sin, religious doctrines help to underscore the stereotypes and myths about disability as being negative and essentially evil.³²⁸ Here we will briefly consider the doctrinal themes of the image of God, sin and heaven, leaving a more in-depth reflection on the biblical account to the normative task in the following chapter.

3.1 Image of God

The way in which the image of God (*imago Dei*) is understood may explain some of the behaviours on the spectrum of disability experiences. If we believe that God's perfection is reflected in the image that we have received, this can affect what we see as normative and how we are meant to treat those who fall outside that norm. Thomas Reynolds sums this up in the following way:

If God is perfect, self-sufficient, and sovereign, the vocation of human beings in the created order can be conceived in like terms... By implication, humans can easily construe their creaturely task – in the image of God – to be one of imposing order on chaos, a chaos equated with the “out of control” body, the abnormal and strange, the monster.³²⁹

In terms of this research it could be said that some behaviours towards people with disabilities may be the result of attempts to maintain a sense of order, or perhaps more correctly a sense of normality, when it comes to church involvement. The experiences recounted particularly under the discrimination and stereotyping headings seem to suggest that this ‘imposing of order on chaos’ type of reasoning could lie subconsciously behind the negative reactions experienced by SDA members with physical disabilities.

³²⁸ Charlton, pp. 63–65.

³²⁹ Reynolds, *Vulnerable Communion*, p. 179.

3.2 Sin

It cannot be denied that there is biblical material that appears to support a negative stereotyping of disability. The following are four well known examples from the Bible that can be said to contribute to these negative attitudes. Leviticus 21:17-23 expresses the prohibition of people with physical disabilities from offering priestly sacrifices. The story in Luke 5:18-26 of the healing of the paralysed man brought by his four friends, suggests that physical healing and forgiveness of sin are equivalent. In John 5, which details the healing of the man by the pool of Bethesda, Jesus later tells him to go and sin no more, again making a connection between his inability to walk and sin. Finally, the story of the man born blind in John 9 shows the common belief in the link between sin and disability, even though this time it is critiqued by Jesus.

Nancy Eiesland states that as long as disability is unaddressed theologically ‘the Christian church will continue to propagate a double-minded stance’.³³⁰ She then examines the American Lutheran Church as an example of how their theology of access, that initially seemed very well intentioned, essentially led to the discriminatory decision that people with disabilities would not be allowed to enter ordained ministry.³³¹ Her conclusion is that a ‘liberatory theology of disability’ is needed which includes, dialogue that has people with disabilities at its ‘speaking center’, an acknowledgement of the role that institutions play in propagating disability, and a call for the church to ‘embody justice as its fundamental mission’.³³²

In the Adventist context, the mixed reactions of church members towards people with disabilities perhaps serve as an example of Eiesland’s double-minded stance. The official statement of our values includes the following:

Our sense of mission is driven by the realization that every person, regardless of circumstances, is of infinite value to God and thus deserving of respect and dignity.

³³⁰ Eiesland, p. 75.

³³¹ Eiesland, pp. 75–86.

³³² Eiesland, p. 87.

Through God's grace every person is gifted for and needed in the diverse activities of the church family.³³³

In fact the recently formed Special Needs Ministries department³³⁴ has as its strapline, 'All are gifted, needed and treasured.'³³⁵ Yet at the same time we cannot overlook the fact that the reactions and actions of some of our members actually indicates that in their minds there is a conflation between sin and disability.

McCloughry suggests that this may have a fear-based connection.

There is a fear in every human being that needs to be dealt with if it is not to become a burden to us. Buried deep within us is the idea that when we are going through difficult times we have in fact displeased God.³³⁶

He goes on to say that even though death comes to everyone it is accepted as natural, whereas disability is viewed as unnatural. Here again it is because, as discussed above under the psychological reasons, disability presents us with a possible future that we would rather not be reminded of.³³⁷

3.3 Heaven

The doctrine of heaven can affect attitudes in a couple of ways. Firstly, it can be conceptualised as God returning everything to its original normal state. For example, Isaiah 35:5-6 describes a time and place where the blind see, the deaf hear, the lame leap and the mute speak. Subconsciously this can reconfirm the ideas behind the 'cult of normalcy' which, Reynolds points out, functions in a way that seeks 'to maintain social control by mainstreaming body capital and remedying or excluding what presents itself as lacking body

³³³ See <https://www.adventist.org/en/information/official-statements/statements/article/go/-/values/> (accessed 22 February 2017).

³³⁴ The General Conference, the administrative body of the Adventist world church, formed a committee to address these needs in 2011, then in September 2015 the ministry was voted to be under direct presidential oversight with an increased global emphasis.

³³⁵ See <http://specialneeds.adventist.org/> (accessed 22 February 2017)

³³⁶ McCloughry, p. 49.

³³⁷ McCloughry, p. 51.

capital’.³³⁸ In other words, the renewal of heaven can be conceived as eventually bringing the disabled back up to where the abled are.

Another way in which the doctrine of heaven can influence attitudes is in pointing to a future time of healing. One of the consequences of this is that the highest ideal expected of a person with disabilities is to endure suffering virtuously, as is exemplified by the apostle Paul’s ‘thorn in the flesh’ (2 Corinthians 12:7-10). As Eiesland articulates, the unfortunate consequence of this is that ‘it has encouraged our passivity and resignation and has institutionalized depression as an appropriate response to “divine testing”’.³³⁹ In other words, the idea of everything being made right in heaven can lead to the expectation that people with disabilities should passively accept the social status quo. Not only can the hero pressure that was alluded to by some of the research participants be seen as an expression of this kind of reasoning, but so too the resistance and discrimination experienced by those who raised their voice in protest at their treatment.

Conclusion

We have explored three fields which seem to provide possible explanations for the experiences of Adventist members with physical disabilities. The negative experiences in particular can be said to have resulted from meeting oppressive and unjust ideas, values and theologies. Hence the liberation element as expressed in the research question that this thesis is pursuing is very pertinent.

Sagely wisdom would suggest that the explanations that have been investigated in this chapter could be usefully introduced into any dialogue endeavouring to explore how to respond appropriately to the gift of the presence of people with disabilities in our congregations. Promoting a sociological, psychological and doctrinal discussion is a way of exploring attitudes without pointing the finger of blame, which would likely elicit a defensive response. Entering into a dialogue is a wiser and healthier way of increasing awareness around the topic of disability which we will explore further in the pragmatic task.

³³⁸ Reynolds, *Vulnerable Communion*, p. 63.

³³⁹ Eiesland, p. 72.

Before that we will need to look at what ought to be going on in our churches based on a balanced theological understanding of disability. This is the purpose of the normative task which we will embark on in the next chapter.

Chapter 7 – A Theological Foundation

(The normative task)

In this chapter, we will be attempting to address the theological challenge that any Christian church seeking to be a place of liberty for people with disabilities needs to come to terms with. Articulated in the words of Nancy Eiesland,

In order for the Christian church to stop doing harm and energize their efforts to be a body of justice, critical and careful attention must be given to a theology of disability as an established feature of the systematic theological enterprise.³⁴⁰

The normative task, in endeavouring to answer the question of what ought to be going on, needs to grapple with the ambivalent picture that comes from the Bible with regards to disability. In this chapter we will be attempting three things. Firstly, we will endeavour to interpret disability with theological concepts. This will specifically involve the three doctrines outlined in the previous chapter: the image of God, sin and eschatology, but will also be expanded to address the priesthood prohibitions in Leviticus 21:17-23.

Secondly, we will explore ethical principles that can provide normative boundaries for guiding and reflecting on practice. Since all actions can be said to be value based, it is important to investigate the ethical positions that may be foundational for the behaviours exhibited towards people with disabilities. Thirdly, we will focus on L'Arche as an example of good practice that can illustrate ways of living in community with people with disabilities that transcend current practice.

1. Theological Explorations of Disability

1.1 The image of God

As highlighted in the previous chapter, the image of God in humankind is one of the concepts that has significant implications for gaining a biblical understanding of disability. In the Old Testament there are only three passages that directly mention the image of God in

³⁴⁰ Eiesland, p. 75.

humankind. The creation story of Genesis 1:26-28 is where the image is first mentioned; it is reiterated in Gen 5:1-3 as an introduction to the genealogy of Adam, and in Gen 9:5-6 when God makes a covenant with Noah. The problem with these texts is that none of them specifically explains what this image is comprised of. This lack of clarity has generated much philosophical speculation as to how the image of God should be understood.³⁴¹

One way in which the image of God could be understood is in terms of capacity. In other words, it is recognised by abilities such as self-consciousness and rationality, and conscious behaviours like morality and creativity. Essentially the expression in Gen 1:26 where God says 'Let us make man in our image, in our likeness, and let them rule...' gives the impression that the image is associated with some form of capacity or agency. In fact, this has been the prominent idea for most theologians throughout much of Christian history.³⁴²

The SDA church can be seen to have leanings towards this explanation. For example, the *Handbook of SDA Theology* says 'The idea of the human creatures as an image of God primarily points toward their role as God's representative over the lower creation... Bearing God's image, then, does not imply so much resembling God as representing Him.'³⁴³ This idea of representation can be found in the concept of stewardship over creation that is implied in the term 'rule' (Heb. *radah*) in Gen 1:26,28.³⁴⁴ However, from a disability perspective, this idea of capacity is problematic. This is primarily because it can imply that the unproductive, those who seem to lack cognitive or physical agency, in some way reflect less of the image of God than others.

The opposite idea of capacity is to define the image of God in terms of latency. In other words, it should be understood as a status that every person possesses regardless of their capacity.³⁴⁵ One way of approaching this is to consider the implications of humankind being

³⁴¹ See for example the historical overview exploring the writings of theologians spanning the century 1882-1982 by Gunnlaugur A. Jónsson, *The Image of God: Genesis 1:26-28 in a Century of Old Testament Research*, Coniectanea Biblica, 26 (Stockholm: Almqvist & Wiksell, 1988).

³⁴² Philip Thomas, 'The Relational-Revelational Image: A Reflection on the Image of God in the Light of Disability and on Disability in the Light of the Image of God', *Journal of Religion, Disability & Health*, 16.2 (2012), 133-53 (pp. 134-36) <<https://doi.org/10.1080/15228967.2012.673083>>.

³⁴³ *Handbook of Seventh-Day Adventist Theology*, ed. by Raoul Dederen, Commentary Reference Series, v. 12 (Hagerstown, MD: Review & Herald Pub. Association, 2000), p. 208.

³⁴⁴ *The Seventh-Day Adventist Bible Commentary: The Holy Bible with Exegetical and Expository Comment.*, ed. by Francis D. Nichol, 7 vols (Hagerstown, MD: Review & Herald Pub. Association, 1978), Vol. 1, p. 216.

³⁴⁵ Thomas, p. 137.

a created person.³⁴⁶ Gen 1:26-28 seems to set up a paradox because it describes humans as creatures that are totally dependent on God, yet at the same time they have a certain amount of independence which prevents them from being merely passive beings, albeit with a relative independence rather than absolute autonomy.

An important further aspect is found in Gen 2:7, 'Then the Lord God formed a man from the dust of the ground and breathed into his nostrils the breath of life, and the man became a living being.' This can be seen as describing the human person in terms of physical and spiritual component parts. It would then be natural to enquire whether only one or both of the components actually reflect the image of God.

In his chapter entitled 'Probing the Mystery of Being Human' Richard Bube describes four main models of human being that have been understood throughout history.³⁴⁷ The first is a purely biological view where humans are seen as one particular species among many creatures. This is typical of evolutionary science. The second is where the spirit is seen as the essence of human being and that we are temporarily housed in a body. Hence the resulting dualism that Platonic thought brought about. The third model is where there are three self-existing parts i.e. body, soul and spirit. In this case the soul and spirit are viewed as immortal and are said to live on after death. The fourth model is where the whole is greater than the sum of the parts. At death the identity is preserved by God until the resurrection. Models two and three can be said to have given rise to the idea that it is the spiritual component that is reflective of the image of God. From an Adventist perspective, the fourth model most closely reflects their understanding.

Since 1863 the SDA church has held a holistic view of human being. This position is attributed to a vision on health that Ellen White reported to have received on June 6 of that year. It was to prove very significant for the development of the health emphasis that Adventists have become known for.³⁴⁸ As expressed in their fundamental beliefs,

³⁴⁶ Anthony A Hoekema, *Created in God's Image* (Exeter: Eerdmans, 1986), p. 5.

³⁴⁷ Ted Engstrom, *The Evangelical Round Table: The Sanctity of Life*, ed. by Fraser (Princeton, NJ: Princeton University Press, 1987), III, pp. 118–37.

³⁴⁸ Teel, p. 130.

Man and woman were made in the image of God with individuality, the power and freedom to think and to do. Though created free beings, each is an indivisible unity of body, mind and spirit, dependent upon God for life and breath and all else.³⁴⁹

Thus, in Adventist understanding, it is the wholeness of a person that can be said to reflect the image of God rather than just one particular part of their being.³⁵⁰ In fact, the SDA view sees humankind's difference from God as also reflective of the image.

From the idea that humans are the only beings created in the image of God, we may indeed infer that they have been created as distinct and unique individuals. Humans are '*akhad* "one," "unique," just as God is '*akhad* "one" and "unique" (Deut 6:4; cf. 1 Cor 8:4-6)... Succinctly stated, humans are in God's image not only because they resemble God physically and spiritually, but also because they have not been created as another "Himself," a mere mechanical reproduction of God, obliged to say "yes" to God, but as free and different beings capable of saying "no" to God.³⁵¹

Here again we observe the use of language that uses capacity to denote the image of God. Thus, it can be concluded that within Adventism the perspective on the image of God in humankind is a somewhat ambiguous mixture of ideas. It expresses both the capacity to choose to reflect God, and the latent status that all people possess by virtue of their existence as whole beings.

This ambiguity is conceivably the result of attempting to arrive at a suitable definition of the image of God based solely on the Old Testament. Due to its lack of explanatory definitions the creation account in the book of Genesis is seen by most theologians as insufficient for understanding the image of God. The New Testament helps to give a more complete picture, as this broadens the context to the whole Christian Bible.

³⁴⁹ General Conference of Seventh-Day Adventists, p. 164.

³⁵⁰ This corresponds with Michael Bube's designation of a human as a 'pneumopsychosomatic' unity, from which he concludes, 'The human being does not *have* life; the living human being *is* alive. The human being does not *have* a body, a soul, and a spirit; the human being *is* a body-soul-spirit, that unique living creature made in the image of God, redeemed by the death of Christ, and destined in Christ (for as many as receive him in faith) to be raised to living experience as a whole person.' See Engstrom, III, p. 136.

³⁵¹ *Genesis*, ed. by Jacques Doukhan, Seventh-Day Adventist International Bible Commentary (Nampa, ID: Pacific Press, 2016), Vol 1., p. 64.

The writers of the New Testament refer to humankind in general being created in the image and likeness of God,³⁵² however the full expression of the image is found in Jesus Christ.³⁵³ Thus we find many theologians arguing that biblical anthropology should begin with Jesus crucified and resurrected. For example, Jürgen Moltmann asserts that 'Christian anthropology is an anthropology of the crucified Lord: it is in relation to this 'Son of Man' that man recognizes his truth and first becomes true man.'³⁵⁴

One of the main ideas that comes from understanding humankind through the person of Jesus is that of relationship. Anthony Hoekema, for example, sees the incarnation of Christ as confirming the image of God in man, arguing that Christ could not have become a creature that had not been created in the image of God. He goes on to conclude that,

What must therefore be at the center of the image of God is not characteristics like the ability to reason or the ability to make decisions (important as such abilities may be for the proper functioning of the image of God), but rather that which was central in the life of Christ: love for God and love for man.³⁵⁵

Numerous scriptural passages suggest that the resurrected Christ is pivotal to understanding humanity's destiny because he embodies the full image of God as is intended for mankind.³⁵⁶ Hence Philip Thomas' conclusion is that the image of God is 'relational-revelational' because it is demonstrated and cultivated in both human and divine relationships, and it reveals God's glory as a person is transformed into the likeness of Christ who is the ultimate goal of humanity.³⁵⁷

Karl Barth is perhaps known as one of the main proponents of relationality as constitutive for human being. As encapsulated in his preferred 'I-Thou' language,

The relationship between the summoning I in God's being and the summoned divine Thou is reflected both in the relationship of God to the man whom He has created,

³⁵² See for example Acts 17:28; 1 Cor 11:7; James 3:9.

³⁵³ See for example 2 Cor 4:4; Col 1:15; Heb 1:3.

³⁵⁴ Jürgen Moltmann, *Man: Christian Anthropology in the Conflicts of the Present* (London: SPCK, 1974), p. 20.

³⁵⁵ Hoekema, p. 22.

³⁵⁶ See for example Rom 8:29; 2 Cor 3:18.

³⁵⁷ Thomas, pp. 141–42.

and also in the relationship between the I and the Thou, between male and female, in human existence itself.³⁵⁸

He makes the point that since God exists in trinity, man reflects this in relation to his original creation as male and female. The ensuing relationality is understood as being free for the other, which also accounts for his Christological understanding of anthropology.

It is because He has come and died and is risen from the dead and will come again that there is Israel and the Church, and hope for all men and all creation. These are irreversible relationships. In all these things He goes before us once for all; not in His humanity as such, for in this respect He makes us Like unto Himself; but in the way in which He is a man, i.e., in virtue of His unique relation to God; and in the fact that we need His humanity in order to be like him as men... Without Him we would not be what we are. What we are must always seek in Him and receive from Him. Our human nature rests upon His grace; on the divine grace addressed to us in His human nature. It is both His and ours, but it is His in a wholly different way from that in which it is ours.³⁵⁹

Barth's idea of being free for the other has been criticised for placing human subjectivity at its centre.³⁶⁰ The problem is that if my humanity is dependent on my being free for another this means that I must be a rational individual, but what would this say about the profoundly intellectually disabled who seem to have no awareness of this kind of relationship? In fact, this critique could be levelled at all the other aforementioned attempts to articulate relationality as constitutive of the image of God. They all seem to demand a certain amount of intrinsic rational capacity.

Hans Reinders offers another perspective. He argues that any reasoning that attempts to account for our humanity as something intrinsic to us will always disadvantage and often exclude the profoundly intellectually disabled, who he sees as being at the bottom of the 'hierarchy of disability'.³⁶¹ His position can be summarised in the claim that,

³⁵⁸ Karl Barth, *Church Dogmatics: The Doctrine of Creation*, trans. by G. W. Bromiley, Thomas F. Torrance, and Frank McCombie, Study ed (London: T & T Clark, 2009), vol. III.1, 196.

³⁵⁹ Barth, vol. III.2, 049-050.

³⁶⁰ Reinders, pp. 242–43.

³⁶¹ Reinders, p. 26.

Being created in God's image indicates a unique relationship; that this relationship is affirmed extrinsically by the triune God, who saves us from failing to respond appropriately to his call; and that this affirmation is offered to us as the fullness of our being.³⁶²

Reinders' insight offers a perspective that potentially levels the playing field for all human beings. If the image of God is seen as the extrinsic gift of his relationship to humankind, then it is given to everyone by virtue of their existence and is essentially independent of their capacity to receive it. Thus, regardless of one's ability the image of God is something given to everyone.

This idea is expanded by Haslam who argues that human being is defined more relationally, by 'one's participation in relationships of mutual responsiveness.'³⁶³ She seeks to avoid an essentialist concept of human being as this would portray individuals with profound intellectual disabilities as deficiently human. Instead she proposes that the image of God is based on seeing God as both desire and the one desired. Thus people with profound intellectual disabilities 'image God not because of some intellectual capacity they possess, but because their participation as responders in relationships is expressive of the longing that God is.'³⁶⁴

An example of a relational understanding within the SDA church is expressed in the writing of theologian V. Norskov Olsen. 'Man is the imago Dei because of his spiritual nature, mental capacity, and moral responsibilities, as well as relational (social) abilities not only with his fellowmen but with the invisible Creator.'³⁶⁵ Here he seems to be attempting to define the image in as comprehensive a manner as possible which results in it being expressed both in terms of capacity and latency. When he later works through the implication of Christ being the image of God Olsen concludes,

³⁶² Reinders, p. 313.

³⁶³ Molly Claire Haslam, *A Constructive Theology of Intellectual Disability: Human Being as Mutuality and Response*, 1st ed (New York: Fordham University Press, 2012), p. 23.

³⁶⁴ Haslam, p. 110.

³⁶⁵ V. Norskov Olsen, *Man, the Image of God: The Divine Design, the Human Distortion* (Washington, DC: Review and Herald Pub. Association, 1988), p. 28.

For the believer, Christlikeness, or being the *imago Dei*, is both a gift and a goal; this truth, or experience, is expressed in the doctrines of justification and sanctification... The Christian life is not so much an imitation of Jesus Christ as habitation for Jesus Christ.³⁶⁶

Here again he seems unable to allow the image to merely be an extrinsically grounded concept, which means his definition would fail the litmus test of applicability to people with profound intellectual disability.

Therefore, we can say that in order for the SDA church to be able to authentically proclaim liberty for people with disabilities, it would need to be brave enough to speak of the image solely in terms of God's gift of his relation to man that is independent of our ability to receive it. Such an extrinsic definition would reflect the original relational declaration in Genesis 1:26-28, and the subsequent expression in the life of Jesus who constantly expressed his self-understanding in terms of his dependent relationship to his Father.³⁶⁷ God's relating to us as whole beings would also reinforce the idea of wholeness on which the SDA health emphasis is built.

1.2 Sin

The main questions for this section are, what effect does sin have, especially on the image of God, and what are the implications for people with disabilities?

If the image of God is understood primarily in terms of relationality, then it can be concluded that sin has damaged but not obliterated it.³⁶⁸ Three prevalent words for sin in the Old Testament give the basic meaning of 'missing the mark' (for example Ps 51:4), intentionally going against God's will (Gen 15:16), and rebellious premeditated violation of a standard (Jer 3:13).³⁶⁹ In the New Testament *hamartia* is used most frequently and means 'missing a mark' (Rom 5:12-13), but there are also words meaning to fall (Matt 6:14-15) and to violate the law (Rom 4:7).³⁷⁰ Thus the *Handbook of SDA Theology* concludes 'The

³⁶⁶ Olsen, p. 178.

³⁶⁷ See for example John 5:19-20; 6:57; 8:42; 10:34-38; 12:44-45.

³⁶⁸ Dederen, p. 236.

³⁶⁹ Dederen, p. 238.

³⁷⁰ Dederen, p. 239.

predominant biblical view of the nature and essence of sin is that of personal estrangement from God. As such it is relational at its core and rebellious in its expression.³⁷¹

The reaction of fear by the first human pair suggests that they were afraid that their sin had lost them God's approval (Gen 3:10). Furthermore, Isaiah 59:2 speaks of the separation that sin brings between God and people so there can be no doubt that sin causes relationship damage. Yet we know that sin has not obliterated the image because God did not immediately cut humans off from relationship with himself. He was the one who took the initiative to seek out humans after the fall (Gen 3:8-9) and give them a prophetic promise of restoration through Jesus (Gen 3:15).

Nevertheless, since the entrance of sin it can be said that the number one obstacle God has had to overcome in us is an underlying fear. As Reinders observes, 'Friendship with God is not the fulfilment of a natural desire. That is, it is not a natural desire in the human condition after the Fall, which is why we have to learn how to receive God's friendship.'³⁷² It is perhaps this fear that undergirds the equating of sin and disability, the fear that disability is the result of God's displeasure. A clear expression of this kind of thinking is found in the question of the disciples in John 9:2, 'Rabbi, who sinned, this man or his parents, that he was born blind?' This story can give us a good insight into God's attitude towards disability as displayed in Jesus.

Jesus clearly denies any connection between sin and this man's disability. Instead he gives the following reason in John 9:3, 'this happened so that the work of God might be displayed in his life.' Jesus' procedure for healing the man was to make mud with his own saliva, apply it to the man's eyes and tell him to wash in the Pool of Siloam (John 9:6-7). Because this took place on a Sabbath the healing was investigated, during which time the man's parents were interrogated and he himself was interrogated twice before eventually being thrown out of the synagogue. At first sight it may seem that the 'work of God' that was displayed in the man's life was his physical healing. However, Jesus' conclusion in John 9:39-41 suggests otherwise.

³⁷¹ Dederen, p. 244.

³⁷² Reinders, p. 310.

The 'work of God' in the gospel of John is clearly defined by Jesus himself in John 6:29, 'The work of God is this: to believe in the one he has sent.'³⁷³ This was clearly revealed by the man himself testifying 'He is a prophet' (John 9:17); 'If this man were not from God, he could do nothing' (John 9:33), and more specifically his direct confession and worship of Jesus (John 9:38). Thus, we can say that it was not so much the healing of disability but rather the man's faith in Jesus that was revealed in the story. This could be used as a template for viewing the healing ministry of Jesus.

Instead of them being seen as the disavowal of a disabled person's worth,³⁷⁴ the healings of Jesus can be viewed as illustrative of God's continued attitude of favour towards humans, in again taking the initiative to re-establish a relationship of trust with himself. Hence, when Luke describes Jesus as reading from Isaiah 61:1-2 to describe his ministry of healing and restoration, the summary of the purpose is 'to proclaim the year of the Lord's favour'. This is consistent with the picture of God in the Old Testament where he is described as healer.³⁷⁵ Because sin has brought a fearful distrust of God's attitude towards humans, healing is illustrative of the way in which God takes the initiative to restore trust to the relationship.

For the SDA church the implication of this would be to articulate its health message as primarily to restore relationship. In other words, to underline the message that all healing processes are illustrative of God's initiative in restoring a trust relationship with himself. This, I would suggest, is the way in which the SDA church can connect its health message with an authentic liberationist position.

The Adventist theologian, Jon Paulien, writes an interesting example of this. He explores whether the Ellen White claim that true education is 'to restore in man the image of his Maker',³⁷⁶ can be said to be a central theme of the Bible.³⁷⁷ From the creation story in Gen 1:26-28, Paulien asserts that the image of God is formulated in terms of three basic

³⁷³ Compare also John 8:39-52; 14:12.

³⁷⁴ Mary Elise Lowe, "'Rabbi, Who Sinned?' Disability Theologies and Sin', *Dialog: A Journal of Theology*, 51.3 (2012), 185-94 (p. 192).

³⁷⁵ See for example Ex 15:26; Ps 103:3; Isa 35:5-6; Jer 30:17.

³⁷⁶ Ellen Gould Harmon White, *Education* (Nampa, ID: Pacific Press, 2002), p. 15.

³⁷⁷ Jon Paulien, 'The Image of God and Educational Philosophy: A Biblical Construct?', *Journal of Research on Christian Education*, 10.Special Edition (2001), 227-57.

relationships, which are towards God, towards others and towards the earth.³⁷⁸ All three relationships were broken in the fall, promised to be restored in the Abrahamic covenant, and restored in the life and death of Jesus Christ. This leads him to conclude that 'Restoring the image of God in beings is nothing less than bringing them into a Mentor-disciple relationship with Him.'³⁷⁹

1.3 Eschatology

The theological concept of eschatology is very central to Adventism. When Adventists write about eschatology the emphasis tends to be placed on the events leading up to the second advent and how to prepare for this momentous event.³⁸⁰ However, from a disability perspective, eschatology raises the question of humankind's ultimate destiny. In other words, what will we be like after the second Advent? The way this is portrayed is deeply significant for people with disabilities because it impacts on how they are perceived and treated today. For example, if our destiny is physical perfection this generally results in people with disabilities being seen as imperfect, especially since the problem of the temporarily non-disabled is that they assume that the incompleteness of people with disabilities is somehow more substantial or significant than their own because of its visibility.³⁸¹

One way of dealing with eschatological expectations is illustrated by Nancy Eiesland. In attempting to present a re-symbolisation of Jesus Christ she makes the claim 'In presenting his impaired hands and feet to his startled friends, the resurrected Jesus is revealed as the disabled God.'³⁸² Her point is that the resurrected Christ demonstrates that the disabled body will be part of physicality in the new earth. It is understandable that this approach has been adopted, because it offers a way to counteract the negative attitudes involved in equating sin with disability and the need to heal the disabled body to make it acceptable. However, as shown in the previous section, there are other ways of conceiving this.

³⁷⁸ Paulien, p. 229.

³⁷⁹ Paulien, p. 249.

³⁸⁰ Dederen, pp. 893–926.

³⁸¹ Thomas, p. 144.

³⁸² Eiesland, p. 100.

One of the fundamental dangers with efforts to describe God as being in solidarity with all forms of disability is that of idolatry. It can come across as attempting to create an understanding of God that is in our image. Contrary to Eiesland's premise, the post-resurrection accounts can be seen to show that the resurrected body of Jesus was actually more enabled than before,³⁸³ as exemplified by his ability to walk through walls (John 20:19) and suddenly disappear (Luke 24:31). In fact, the primary reason for the emphasis on Jesus' wounds in John 20 seems to be to help verify his identity rather than anything else.³⁸⁴ Therefore caution should be exercised in making any specific claims about the significance of the physical wounds of the post-resurrection Christ. To press this even further, should this way of conceiving God be applied to all disabilities including intellectual disabilities? Would proponents of this 'God in solidarity' idea be just as comfortable conceiving God as being learning disabled or is this solely reserved for physical disabilities?

Perhaps the most common way of expressing humankind's eschatological goal is to think of it as a return to the original Edenic perfection.³⁸⁵ There is no doubt that the hope of a time when all suffering is eliminated, as described in Rev 21:4, is a very powerful factor in the psyche of Christianity. However, the way in which this is portrayed is also significant. Adventists would need to ask whether their descriptions of life on the new earth betray an unconscious desire for and expectation of a return to ideal functionality or normality. Not only could this kind of perfect uniformity imply a diminishing of diversity, with all bodies looking and functioning the same, but it would also reinforce the discriminatory idea that people with disabilities are less than ideal or abnormal.

Thus, if the SDA church is to be a place of liberation for people with disabilities it will need to be careful that the way it portrays life on the new earth does not convey the idea of a return to normality. Hence the need to articulate eschatological expectations in terms that are not merely the antithesis of anything associated with disability.

Another way of regarding our eschatological goal is to see disabilities as continuing in the eschaton but losing their significance. Amos Yong is an example of a theologian who takes

³⁸³ John Swinton, 'Who Is the God We Worship? Theologies of Disability; Challenges and New Possibilities', *International Journal of Practical Theology*, 14.2 (2010), 273–307 (p. 284).

³⁸⁴ Thomas, p. 149.

³⁸⁵ Dederen, p. 957.

issue with all 'normate' interpretations of the Bible and offers instead a disability hermeneutic to the scriptures.³⁸⁶ In so doing he argues that 'the resurrected body does not necessarily have to be free of the marks of our present impairments; rather, the resurrection will transform not only our bodies but also the world's scale of values as a whole.'³⁸⁷ He reasons that since Paul in 1 Corinthians 15 describes that there will be some form of continuity between the present and the future body,³⁸⁸ and since Christ's resurrection body also retained the marks of impairment,³⁸⁹ then the same is possible for all who will be resurrected. In fact, some would argue that it is the scars from our present bodies that will enable us to be recognised in the eschaton without diminishing our perfection.³⁹⁰

My argument is that there will be no more tears in the eschaton not because our impairments will be eliminated but because they will be redeemed. By this I am not insisting that people with disabilities will exist literally as such eschatologically... My point is to challenge the absence of disability images altogether in the Christian eschatological imagination.³⁹¹

Yong's approach gives Adventists an interesting point of reflection as to why eschatological conceptions describe the elimination of all disability and how this impacts on attitudes towards people with disabilities in the present. However, his disability hermeneutic runs the danger of downplaying the immense good that God has in store in the eschaton. Since Yong seems to prefer a more social understanding of disability it is easier for him to make the case that the significance of disability can be eliminated by a change in societal attitude. However, this does not take into account the sincere desire on the part of some people with disabilities not to have their impairments.

While it may be argued that this desire is merely an example of an internalisation of society's normate standards, there is no doubt that some people, my son included, truly

³⁸⁶ Yong, p. 13.

³⁸⁷ Yong, p. 122.

³⁸⁸ Yong, p. 123.

³⁸⁹ Yong, pp. 125–30.

³⁹⁰ See for example, Nicola Janet Santamaria, 'Will There Be Tiers in Heaven?: An Examination of the Implications of the Resurrection of the Body for Disabled People' (King's College London, 2014).

³⁹¹ Yong, p. 135.

hope for a world where their pain and deformities no longer exist. Furthermore, if the pain of disabling conditions will be removed in the eschaton why should we not expect the deformities also to be eliminated? To argue strongly for the continuity of disabled bodies into the eschaton also runs the risk of having to identify people with their physicality which is in fact what is usually argued against. In other words, a person is more than their disability. If we have a relational understanding of the image of God then we will understand that the physical form of the resurrection body is of secondary importance to the restored relationship we will have with God.³⁹² In fact this is one of the things that disability can teach, the need to be very humble about what we attribute to our physical abilities in the present world because we are all incomplete.

If we consider 1 Corinthians 15:35-57, which is the passage that most extensively deals with the resurrection body, we can see that the main tenor of the message is to remind us that the body we now have is incomplete. Paul's metaphor of the seed answers the challenge that if disabilities are completely removed, how will people with identity constitutive disabilities be recognised?³⁹³ Just as the seed differs from the plant that grows, so the seed of our present body will not be the same as that which will be at the resurrection (verses 37-38, 42-44). Hence his statement in verse 51, 'Listen, I tell you a mystery: We will not all sleep, but we will all be changed.'

In attempting to understand the resurrection body we may need to embrace the tension that the apophatic tradition suggests.³⁹⁴ The underlying premise behind apophaticism is that what we can know about God is dependent on what he reveals about himself, thus we have to accept a certain amount of mystery because God is beyond all human categorisation. Thus, it would perhaps be easier for us to make correct statements about what God is not rather than what he is.³⁹⁵ That being the case, the same could be applied to humans made in God's image.³⁹⁶ Thus the apophatic tradition teaches the need for humility

³⁹² Thomas, p. 149.

³⁹³ Yong, p. 121.

³⁹⁴ Frances Margaret Young, *Brokenness and Blessing: Towards a Biblical Spirituality*, pp. 44–57.

³⁹⁵ Swinton, 'Who Is the God We Worship?', p. 301.

³⁹⁶ Swinton, 'Who Is the God We Worship?', p. 302.

in making assertions about our future, but also the need to embrace the mystery of human being.³⁹⁷

This can perhaps be summarised in a couple of biblical statements. First is Paul's statement in 1 Corinthians 2:9 that 'No eye has seen, no ear has heard, no mind has conceived what God has prepared for those who love him.' In other words, it would be more accurate for us to say that we do not know, we cannot conceive or imagine, what our resurrection bodies will be like. Second is John's statement in 1 John 3:2, 'Dear friends, now we are children of God, and what we will be has not yet been made known. But we know that when he appears, we shall be like him, for we shall see him as he is.' Particularly instructive is his observation that 'what we will be has not yet been made known.' This is significant because John opens his letter by saying 'That which was from the beginning, which we have heard, which we have seen with our eyes, which we have looked at and our hands have touched – this we proclaim concerning the Word of life.' (1Jn 1:1) Therefore by implication this would mean that Christ's resurrection body should not be used as a defining example of what we will be.

1.4 Priestly prohibitions

The most directly ableist passage in the Bible is arguably that which is found in Leviticus 21:17-23.

¹⁷ "Say to Aaron: 'For the generations to come none of your descendants who has a defect may come near to offer the food of his God. ¹⁸ No man who has any defect may come near: no man who is blind or lame, disfigured or deformed; ¹⁹ no man with a crippled foot or hand, ²⁰ or who is a hunchback or a dwarf, or who has any eye defect, or who has festering or running sores or damaged testicles. ²¹ No descendant of Aaron the priest who has any defect is to come near to present the food offerings to the Lord. He has a defect; he must not come near to offer the food of his God. ²² He may eat the most holy food of his God, as well as the holy

³⁹⁷ John Gillibrand, *Disabled Church - Disabled Society: The Implications of Autism for Philosophy, Theology and Politics* (London: Jessica Kingsley Publishers, 2010), p. 72.

food; ²³ yet because of his defect, he must not go near the curtain or approach the altar, and so desecrate my sanctuary. I am the Lord, who makes them holy.”

Yong highlights the three most common hermeneutical approaches that have been used to interpret this passage.³⁹⁸ The first approach is to separate civic, ceremonial and moral laws. The benefit of this is that civic laws can be said to only apply to ancient Israel and not to today. Ceremonial laws can all be said to have found their fulfilment in Christ, whereas the moral law would still be valid today. As Yong points out, the problem with this approach is that separating these laws is not an easy task, and furthermore doing so would still not provide a satisfactory understanding of these priestly prohibitions.³⁹⁹

The second hermeneutical approach is to read the Old Testament metaphorically thereby looking for spiritual rather than literal applications. Adventists would find this difficult to accept because it does not take what the text says seriously. In his chapter entitled ‘Biblical Interpretation’, Adventist scholar Richard Davidson describes one of the methods used by Adventists in doing theological study as the ‘grand central theme perspective’.⁴⁰⁰ This is where a specific passage is interpreted within the wider context of the central theme of scripture which encompasses the following seven main stages: creation, the fall, the promise and the people, the fulfilment in Jesus, the fulfilment and the people, the day of the Lord, and the new creation.⁴⁰¹ From this perspective one of the questions asked about any passage is how it contributes to the understanding of the grand central theme. This would be taken together with an understanding of the historical context in seeking to determine what the passage meant in its original setting, before attempting to make any contemporary applications.⁴⁰²

The third approach is to read Leviticus Christologically, thus seeing the whole sacrificial system of the Old Testament as being fulfilled in Christ. As Yong points out however, the Christological approach actually ends up making the situation worse for people with

³⁹⁸ Yong, pp. 24–29.

³⁹⁹ Yong, pp. 24–25.

⁴⁰⁰ Dederen, p. 80.

⁴⁰¹ For an explanation of the seven stages together with a schematic illustration see Jan Barna, ‘The Grand Story’, *Ministry*, 84.3 (2012), 21–24.

⁴⁰² Dederen, p. 70.

disabilities because 'It highlights their unacceptable condition simply by emphasizing the perfect body of God's once-for-all priestly representation and finally acceptable sacrifice.'⁴⁰³

Yong's solution is to understand the priestly prohibitions from the wider context of the Old Testament. He uses three stories from the Old Testament. Firstly, the story of Jacob's struggle and ensuing disability is used to point out that it 'serves as a reminder of Israel's covenantal relationship with God'.⁴⁰⁴ So it can be said that disability is a sign of covenant blessing. Secondly, the story of Mephibosheth is used to show how disability can be seen as part of Israel's self-understanding.⁴⁰⁵ Thirdly, the story of Job is used to illustrate how reading it as a trial narrative brings out the redemptive reversal of what may be considered monstrous to actually be magnificent. Just as God uses the examples of monstrous creatures such as the Leviathan and the Behemoth to illustrate his creative genius, so Job's monstrous appearance and suffering are to be viewed as central rather than peripheral to human embodiment.⁴⁰⁶ Even though this wider context does bring some balance to the picture of Old Testament attitudes towards people with disabilities, one is still left with the question of why the priestly prohibitions were articulated in the first place.

In order to come to a more disability-friendly understanding of this passage the idea of the grand central theme is very useful. This forces us to ask what the message would have meant for the original audience. The nation of Israel had been the victim of four hundred and thirty years of conditioning where their worth was measured by their agency (Ex 12:40-41). During the time between their liberation and entering the promised land God was seeking to imprint on them a new identity in which he was central.⁴⁰⁷ One aspect of this was to help them see that they should no longer define themselves by their ability to work but rather in their ability to trust him and rest in his good providence.

For example, Exodus 16:22-29 illustrates how God endeavoured to teach the Israelites to prepare to take Sabbath rest by gathering twice as much manna on the sixth day. However, some still did not follow his instructions and went to look for manna on the seventh day.

⁴⁰³ Yong, p. 29.

⁴⁰⁴ Yong, p. 31.

⁴⁰⁵ Yong, pp. 32-34.

⁴⁰⁶ Yong, pp. 38-40.

⁴⁰⁷ Craig G Bartholomew and Michael W Goheen, *The Drama of Scripture: Finding Our Place in the Biblical Story* (London: S.P.C.K, 2006), p. 50.

Given their slowness in comprehending the lessons of God, the language of the priestly prohibitions can be understood as God's way of reinforcing the idea that in representing him they must give of their best.

This does not mean that people with disabilities should be viewed as worse than others, but in establishing the rules of the priesthood God could be seen as understanding that centuries of conditioning cannot be reversed overnight. Therefore, this passage in Leviticus is an example of God using ableist descriptions that a nation of recently liberated slaves was accustomed to, in order to underscore his holiness. This can be contrasted with later in Israel's history where God uses descriptions of unattractiveness and brokenness in Isaiah 53 to represent himself in Jesus.

Therefore, understanding God's willingness to contextualise his instructions would mean that contemporary applications of the priestly prohibitions would focus more on how God contextualises his message to us today rather than looking for implications for disability.

2. A Basis for Adventist Ethics

Ethical thinking forms part of the interpretive task because our actions and practices are predicated on the norms and values that we hold. Hence the way in which we treat people with disabilities will to a certain degree be determined by our moral reasoning. Ethical thinking is concerned with seeking to understand how we arrive at the right thing to do and also includes consideration of who decides.⁴⁰⁸

The main schools of thought dealing with ethics can be divided into three approaches: consequential, deontological and virtue ethics. Consequential ethics reasons that decisions should be made based on doing the greatest good for the most amount of people, which is also known as the utilitarian position.⁴⁰⁹ This can lead to a situational type of ethics which, from an Adventist perspective, would not be given much credence.

⁴⁰⁸ Neil Messer, *SCM Studyguide to Christian Ethics* (London: SCM Press, 2006), p. 9.

⁴⁰⁹ Browning, p. 100.

The deontological approach to ethics is based on the premise that there are absolute moral duties that should be followed.⁴¹⁰ Immanuel Kant (1724-1804) formulated this as the ‘categorical imperative’, which is the idea that we should behave in such a way as if our actions would be a universal law.⁴¹¹ Due to their somewhat conservative reading of the Bible, Adventists tend to lean towards a more deontological approach to ethics. This naturally leads to questions regarding the sources that Adventists use for direction and authority when it comes to making moral decisions.

Hays suggests that apart from scripture, the other sources that Christians look to for authoritative moral guidance are tradition, reason and experience.⁴¹² Combining reason and experience as sources for moral decision-making, Pearson observes that the imminent return of Christ and the idea of the remnant are the two major doctrines that influence Adventist moral thinking.⁴¹³ He goes on to point out that the idea of the remnant that needs to perform its primary role of faithful obedience to God’s requirements has had a huge impact on Adventist ethics.⁴¹⁴ This need to ‘get it right’ coupled with a strong desire to maintain unity in its very diverse membership, helps to explain why Adventists generally begin their approach to ethical questions from a deontological position.

When it comes to the idea of tradition however, Adventists would be somewhat uncomfortable with using the term because of its association with churches that place tradition equal to, if not above, the Bible. Nevertheless, practically speaking, the writings of Ellen G. White are used as the authoritative tradition within Adventism.

The subject of disability is hardly addressed in Ellen White’s writings. However, in a chapter entitled ‘Duty to the unfortunate’ she makes the following clear statement:

I saw that it is in the providence of God that widows and orphans, the blind, the deaf, the lame, and persons afflicted in a variety of ways, have been placed in close Christian relationship to His church; it is to prove His people and develop their true

⁴¹⁰ Messer, p. 67.

⁴¹¹ Immanuel Kant and Mary J. Gregor, *Groundwork of the Metaphysics of Morals*, Cambridge Texts in the History of Philosophy (Cambridge: Cambridge University Press, 1998), p. 15.

⁴¹² Richard B. Hays, *The Moral Vision of the New Testament: Community, Cross, New Creation; a Contemporary Introduction to New Testament Ethics*, Reprint (London: Continuum T&T Clark, 2007), pp. 209–11.

⁴¹³ Pearson, p. 17.

⁴¹⁴ Pearson, p. 23.

character. Angels of God are watching to see how we treat these persons who need our sympathy, love, and disinterested benevolence. This is God's test of our character.⁴¹⁵

Further on in this reference she makes mention of the conclusion to the parable of the sheep and goats in Matthew 25, that whatever is done for the least is done for Christ. She also uses the example of Achan from Joshua 7 to make the observation that God sees the community as sinning if some in their midst mistreat a person with disability. In doing this White seems to be implying that an indication of good ethical behaviour is shown by the demonstration of the attribute or virtue of love. In other words, when it comes to questions relating to the treatment of people with disabilities, White seems to suggest that virtue rather than deontological reasoning would provide the best guide.

Speaking of virtue is a way of explaining how we become what we do.⁴¹⁶ The idea first came about from Plato, Aristotle and the Stoics who described the good life, or a life of flourishing, as hinging on the 'cardinal virtues'⁴¹⁷ of temperance, courage, prudence (practical wisdom) and justice. These were not the only virtues but all other virtues were seen as contingent on these four. Aquinas later gave a more systematic Christian treatment of virtue, adding the three theological virtues of faith, hope and love.⁴¹⁸

The philosopher Alasdair MacIntyre is one of the most influential modern thinkers to argue for a virtue ethic. He critiques the competing ethical frameworks that have been espoused by philosophers from the Enlightenment and onwards, and concludes that it has resulted in a fragmentation of moral standards. This is due to a failure to take into account our situatedness in history and thus the narrative nature of ethics.⁴¹⁹

From a modern Christian perspective, Stanley Hauerwas is one of the greatest proponents of virtue ethics. He believes that Aristotle and Aquinas gave a good start in understanding virtue but that they failed to take into account the importance of narrative in developing

⁴¹⁵ Ellen G. White, *Testimonies for the Church* (California: Pacific Press Publishing Association, 1948), III, p. 511.

⁴¹⁶ Stanley Hauerwas and Samuel Wells, *Living Out Loud: Conversations about Virtue, Ethics, and Evangelicalism* (Paternoster, 2010), p. xi.

⁴¹⁷ From the Latin 'cardo' meaning 'hinge.'

⁴¹⁸ Messer, p. 130.

⁴¹⁹ Alasdair C. MacIntyre, *After Virtue: A Study in Moral Theory*, 3rd ed (Notre Dame, Ind: University of Notre Dame Press, 2007).

virtue.⁴²⁰ Hauerwas explains that Christians are a 'story-formed' community just like any other community (whether British, communist, etc). Thus, we are narrative based and our ethics will therefore be narrative based. From a Christian perspective, the narrative we inhabit is the history of God's dealing with Israel and Jesus in particular. Therefore the Christian community, in his estimation, is about keeping the biblical stories alive and applying them to contemporary situations.

Hauerwas argues that Christian ethics is not so much about finding laws and principles to live by but rather about paying attention to the life of Jesus.⁴²¹ Since learning to be moral is not something that is arrived at alone but rather learnt from relationship to others, this would demonstrate why a teacher is necessary, why learning in a relationship is key, and why understanding the history of the tradition and one's place in that history is important. Thus, he uses the analogy of apprenticeship and learning a craft to illustrate the moral life.⁴²²

If virtue is seen as being primarily concerned with anticipating in the present that which we hope for in the future,⁴²³ the Adventist emphasis on wholeness as outlined in the introduction above is quite appropriate. However, a disability perspective would necessitate a vital adjustment. The SDA church would need to expand its idea of health to incorporate church and community health in addition to the individual focus that it has at present. By so doing, it would bring about a correspondence to the wholeness models that can be found in the biblical passages that speak of the full participation of people with disabilities in the community of faith.⁴²⁴

Furthermore, Moltmann makes the very insightful observation that 'True health is the strength to live, the strength to suffer, and the strength to die. Health is not a condition of my body; it is the power of my soul to cope with the varying condition of that body.'⁴²⁵ Taking this into consideration, it could be said that the health of the SDA community can be

⁴²⁰ Stanley Hauerwas, *The Peaceable Kingdom: A Primer in Christian Ethics* (Notre Dame, Ind: University of Notre Dame Press, 1984).

⁴²¹ Hauerwas, p. 76.

⁴²² Hauerwas and Wells, pp. 39–59.

⁴²³ Tom Wright, *Virtue Reborn* (London: Society for Promoting Christian Knowledge, 2010), p. 82.

⁴²⁴ See for example 1 Cor 12:21-27.

⁴²⁵ Moltmann, p. 142.

measured by the spirit with which it handles the opportunities that people with disabilities present the body of Christ with. In other words, the benefit of a disability-focused virtue ethic for the SDA church is that it would steer the denomination towards corporate wholeness.

3. A Model of Good Practice

As mentioned above, L'Arche started in 1964 under the leadership of Jean Vanier and is now an international federation of communities where people with and without learning disabilities live and share life together.

Although the research for this dissertation did not focus on learning disabilities, I believe L'Arche provides important principles that can serve as a model for how the Adventist church can authentically proclaim liberty for people with disabilities. However, these lessons should not be taken to mean that L'Arche is the ideal community that all should follow. Scholars within disability studies have offered several critiques especially of L'Arche's language of brokenness, its framing of disability, its underlying religiosity, its charitable model of care, its lack of attention to broader socio-political change, and the dominance of Jean Vanier as its charismatic founder.⁴²⁶ Despite these reservations however, L'Arche shows in practice what living in communion with people with disabilities can look like. Hence, we will focus on the three areas of attitude, healing and transvaluation.

3.1 Attitude

The first principle that L'Arche models well is the attitude of those who serve within its community. John Swinton observes that 'L'Arche is a place where disabilities exist, but don't really matter.'⁴²⁷ This is because the theology and philosophy of L'Arche teaches that disability is not a problem that needs solving, but rather a way of being human which should

⁴²⁶ For a discussion of these issues see, Madeline Burghardt, 'Brokenness/Transformation: Reflections on Academic Critiques of L'Arche', *Disability Studies Quarterly*, 36.1 (2016) <<https://doi.org/http://dx.doi.org/10.18061/dsq.v36i1>>.

⁴²⁷ John Swinton, 'The Body of Christ Has Down's Syndrome: Theological Reflections on Vulnerability, Disability, and Graceful Communities', *The Journal of Pastoral Theology*, 13.2 (2003), p. 68.

be understood, valued and supported.⁴²⁸ Therefore L'Arche provides a good example of a community where the meaning of disability is very different from that of the dominant culture. To learn from this the SDA church will need to acknowledge the existence of disability but make its meaning something positive rather than negative. This is partly why the theological discussion of the previous section is so important. In order to have a good theological foundation, certain ableist-sounding scriptures need to be grappled with in order to make the meaning of disability something positive rather than negative.

Vanier observes that 'The belief in the inner beauty of each and every human being is at the heart of l'Arche.'⁴²⁹ Thus it is a community that is built on welcoming and accepting all people as unique gifts who have 'divine dignity, meaning and purpose'.⁴³⁰ The effect of this is the development of an attitude of love towards people for who they are, not for what they can do for us, which in turn can help us to learn to love God for who he is rather than what he can do for us.⁴³¹ Living in a society that is built on the exchange of goods, whether material, psychological or social, this idea is quite radical. This means that in the development of pastoral care within the SDA church it will be important that people are helped to develop the ability to love God for his own sake and other people for their own sake.⁴³² L'Arche is an example of what this can look like in practice.

3.2 Healing

The second principle that L'Arche demonstrates well is that of healing. From his experience of living in L'Arche, Vanier observes that the source of greatest pain for people with disabilities is not necessarily physical discomfort but rather 'the feeling that nobody really wants you "like that." The feeling that you are seen as ugly, dirty, a burden, of no value.'⁴³³ This highlights the deep need for communion which all people have. Vanier defines communion as being with someone and accepting them just as they are with their limits and their gifts, walking with a person through their pain, and allowing people to be themselves

⁴²⁸ Ibid.

⁴²⁹ Vanier, *Becoming Human*, p. 23.

⁴³⁰ Swinton, 'The Body of Christ Has Down's Syndrome', p. 68.

⁴³¹ Swinton, 'The Body of Christ Has Down's Syndrome', p. 69.

⁴³² Swinton, 'The Body of Christ Has Down's Syndrome', p. 69.

⁴³³ Vanier, *From Brokenness to Community*, p. 13.

without dictating how they should be.⁴³⁴ Interestingly Vanier confesses that it was this last aspect which was the area of greatest growth for himself as he discovered his own poverty and pain,⁴³⁵ and it is a necessary stage of development for everyone who comes to L'Arche. 'People may come to our communities because they want to serve the poor; they will only stay once they have discovered that they themselves are the poor.'⁴³⁶ Consequently forgiveness, first for oneself then for others, is such an integral part of life in the L'Arche community.⁴³⁷

Once this discovery has been made then true healing relationships can be developed. 'As we interact with broken people, be it in L'Arche or elsewhere, we enter into this flow of life, that mutual trust and affirmation between people, giving life one to another, discovering our mutual fecundity and fruitfulness.'⁴³⁸ Thus healing transformation is not a one-way street but is more reciprocal in nature. 'It is not just a question of performing good deeds for those who are excluded but of being open and vulnerable to them in order to receive the life that they can offer; it is to become their friends.'⁴³⁹

In order for the SDA church to become a disability liberating community it would do well to learn from L'Arche the need for developing genuine friendships with people with disabilities. Because of their reciprocal nature these friendships will bring healing for all and not just people with disabilities. In other words, the benefit of bringing more focus to the area of disability is that it will expand the Adventist health message to include healing and wellness for whole church communities.

3.3 Transvaluation

The third principle that L'Arche models is that of transvaluation. Swinton defines transvaluation as where a 'personal encounter with people with profound developmental disabilities initiates a movement towards a radically new system of valuing.'⁴⁴⁰ He argues

⁴³⁴ Vanier, *From Brokenness to Community*, pp. 16–18.

⁴³⁵ Vanier, *From Brokenness to Community*, p. 18.

⁴³⁶ Vanier, *From Brokenness to Community*, p. 20.

⁴³⁷ Vanier, *Community and Growth*, pp. 35–38; Vanier, *Becoming Human*, pp. 135–63.

⁴³⁸ Jean Vanier, *The Broken Body* (London: Darton, Longman and Todd, 1988), p. 84.

⁴³⁹ Vanier, *Becoming Human*, p. 84.

⁴⁴⁰ Swinton, 'The Body of Christ Has Down's Syndrome', p. 67.

that if our relationships form who we are as persons⁴⁴¹ then if we were to have friendships with people who are very different to us (such as those with learning disabilities) then transvaluation would be the natural result. This is the main foundation for L'Arche. As Vanier himself states,

Our focal point of fidelity at l'Arche is to live with people who have a handicap, in the spirit of the Gospel and the Beatitudes. 'To live with' is different from 'to do for'. It doesn't simply mean eating at the same table and sleeping under the same roof. It means that we create relationships of *gratuité*, truth and interdependence, that we listen to our people, that we recognise and marvel at their gifts, and particularly their openness to God and their holiness. The day we become no more than professional workers and educational therapists is the day we stop being l'Arche – although of course 'living with' does not exclude this professional aspect.⁴⁴²

Thus L'Arche exemplifies a community that has learnt to value difference without the need to pathologize those differences.⁴⁴³

In its current discussions of issues connected with diversity,⁴⁴⁴ the SDA church also has the opportunity to experience the same transvaluation as exhibited by L'Arche. This transformation of values will take place as it seeks to highlight the importance of growing true friendships with people with disabilities and to foster the development of such relationships.

Conclusion

This research project is seeking to investigate how the SDA church with its emphasis on health can authentically proclaim liberty for people with disabilities. Hannah Lewis, in her exploration of a deaf liberation theology, presents what she believes a 'liberating-shaped

⁴⁴¹ Swinton, 'The Body of Christ Has Down's Syndrome', p. 74.

⁴⁴² Vanier, *Community and Growth*, p. 150.

⁴⁴³ Swinton, 'The Body of Christ Has Down's Syndrome', p. 75.

⁴⁴⁴ See for example, Reinder Bruinsma, 'Diversity: A Biblical Paradigm', *Spectrum Magazine*, 42.3 (2014), 19–26; Richard de Lisser, *Diversity: The Challenge for Contemporary Adventism* (Middlesex: Cross Culture Media, 2015).

church' will look like.⁴⁴⁵ The main characteristic is that of space. This is the kind of space where the pace of church life is slow enough to include all, such as those needing more time for deaf interpretation. It is a space where people with disabilities are valued as equal and not as lesser beings needing healing. It is also a space where leadership opportunities are available for people with disabilities, where the stories that are told also include those of people with disabilities, and where people are encouraged to express their relationship with God in a creative manner.

Thus, in performing theological and ethical interpretation and providing examples of good practice, we have illustrated how SDA churches can be labelled as liberating-shaped for people with disabilities. Engaging in the task of prophetic discernment can help to foster fellowships that will be known for creating a disability space because of the attitude of its members, the healing relationships that are nurtured and the transformation of its core values.

The question that remains is therefore how to bring about the necessary changes in order to create this liberating-shaped community. This will be addressed in the next chapter.

⁴⁴⁵ Hannah Lewis, *Deaf Liberation Theology*, Explorations in Practical, Pastoral and Empirical Theology (Aldershot: Ashgate Publishing Limited, 2007), pp. 179–83.

Chapter 8 – The Way Forward

(The pragmatic task)

The pragmatic task is the action stage of the practical theological process. As defined by Osmer, it is 'The task of forming and enacting strategies of action that influence events in ways that are desirable.'⁴⁴⁶ This is achieved by giving a general picture of the discipline under discussion together with more specific suggestions for carrying out certain actions or procedures. Because the research findings in chapter 5, which we described as the descriptive-empirical task, seem to indicate that a change is needed in the way people with disabilities are treated in some Adventist churches, this chapter will focus on the general topic of leading change.

Throughout this thesis the language of oppression and liberation have been used somewhat freely, so it would be appropriate at this point to briefly acknowledge how I see liberation theology impacting on the research question. Liberation theology arose in the 1960s and 1970s as a result of the growing realisation among a minority of church leaders in Latin America that the church was perpetuating the exploitative conditions that were being suffered by the majority of the population in their countries.⁴⁴⁷ In countries like Brazil, Peru and El Salvador conditions of abject poverty, violence and injustice combined with manipulative colonising influences to produce an extremely oppressive situation. This led to a commitment by these leaders to fight for liberation both socially and politically. Names associated with liberation theology include Gustavo Gutierrez from Peru,⁴⁴⁸ Clodovis and Leonardo Boff from Brazil,⁴⁴⁹ and Juan Luis Segundo from Uruguay.⁴⁵⁰

Gutierrez defines liberation theology as 'a critical reflection on Christian praxis in light of the word of God'.⁴⁵¹ Some of the elements that characterise liberation theology are as follows. Firstly, it starts with a commitment to the poor by helping them become conscious of their

⁴⁴⁶ Osmer, p. 176.

⁴⁴⁷ Stephen Pattison, *Pastoral Care and Liberation Theology* (London: SPCK, 1997), p. 24.

⁴⁴⁸ Gustavo Gutierrez, *A Theology of Liberation: Fifteenth Anniversary Edition*, ed. by Sister Caridad Inda and John Eagleson, Revised edition (New York: Orbis Books, 1988).

⁴⁴⁹ Leonardo Boff and Clodovis Boff, *Introducing Liberation Theology*, trans. by Paul Burns (Tunbridge Wells: Burns and Oates, 1992).

⁴⁵⁰ Juan Luis Segundo, *The Liberation of Theology*, trans. by John Drury (Maryknoll, N.Y: Orbis Books, 1976).

⁴⁵¹ Gutierrez, p. xxix.

situation and giving them the tools with which to break out from their oppression,⁴⁵² in other words it is a change process that is taken on by the poor themselves and not something done on their behalf.⁴⁵³ Secondly, it does critical theological reflection mainly using the social sciences (particularly Marxism) to explore socio-political sources of oppression.⁴⁵⁴ Thirdly, it uses a hermeneutic circle⁴⁵⁵ as a practical theological methodology that calls for liberation of the poor.⁴⁵⁶ Given these characteristics it would be more accurate to say that the change process of this thesis is not intended to be an example of liberation theology. Rather it is a liberating exercise of 'critical solidarity'⁴⁵⁷ with people with disabilities in the SDA church that hopes to bring about a change in the way they are viewed and treated.

Other approaches to change draw upon insights and practices from the business world and so it will be business principles that this chapter will engage with. Consequently, here at the outset it is important to acknowledge that there is a tension involved in attempting to use organisational change principles from the business world and applying them to churches. Business principles are predicated on assumptions about organisations that deal with markets, products and profits. The church, on the other hand, is seen as a spiritual entity that is led by Jesus Christ and empowered by the Holy Spirit.⁴⁵⁸ One of the overriding metaphors by which the church is conceived is that of a body, an organic system where all the parts are equally important and in fact where the weaker parts are accorded special honour.⁴⁵⁹ Hence the church will consequently be expected to function differently than profit-seeking organisations.⁴⁶⁰ Having acknowledged this caveat, we can proceed to explore some organisational change principles that can be deemed applicable in a church setting.

⁴⁵² Boff and Boff, p. 5.

⁴⁵³ Pattison, p. 29.

⁴⁵⁴ Swinton, *Resurrecting the Person*, p. 14.

⁴⁵⁵ Defined by Segundo as 'the continuing change in our interpretation of the Bible which is dictated by the continuing changes in our present-day reality, both individual and societal.' Segundo, p. 8.

⁴⁵⁶ Segundo, p. 33.

⁴⁵⁷ Swinton, *Resurrecting the Person*, p. 16.

⁴⁵⁸ Adventist, pp. 165–67.

⁴⁵⁹ See 1 Corinthians 12:21–25.

⁴⁶⁰ See for example, Don Cousins, *Experiencing LeaderShift: Letting Go of Leadership Heresies* (Colorado Springs: David C. Cook, 2008). The author explores four leadership heresies that he believes have caused damage in the church, namely: the success heresy, the serving heresy, the credit heresy and the organisational heresy.

One of the major debates within the field of organisational change is whether change takes place as a process of gradual evolutionary steps or in larger revolutionary episodes, and what role leaders play in the process.⁴⁶¹ Given the many different theories and categories of change that have been articulated to date, Burnes offers a very useful framework that can indicate the kind of change that is necessary in the SDA church if it is to authentically become a place of liberation and equality for people with disabilities.⁴⁶²

The framework is divided into four quadrants. The two quadrants in the top half represent situations where large-scale, organisation-wide changes need to be made to either structures or cultures. This is mainly due to the turbulent environment in which the organisation is operating. The bottom half of the framework is for organisations who need to make small-scale but sustainable changes to an individual's or group's attitudes and behaviours or procedures and tasks. This requires a more stable environment.

The two quadrants on the left side of the framework denote instances where change is focused on the human side of the organisation thus incorporating attitudinal, behavioural and cultural change. Burnes points out that these types of changes require more slow and participative processes.⁴⁶³ This contrasts with the two quadrants on the right side of the framework that signify instances where the focus of change is on the technical side of the organisation such as tasks, procedures, structures and processes. These usually require more rapid change processes.⁴⁶⁴

This framework is useful because it suggests that the type of change that should form the basis of this pragmatic task should primarily be focused on the human side of the Adventist organisation, with a more specific focus on individual and group attitudes, behaviours and tasks. In other words, we will be seeking to illustrate a slower small-scale process rather than a large-scale rapid revolutionary change. Hence, this chapter will be divided into two main sections. The first part will examine the significance of the leader in the change

⁴⁶¹ Christiane Demers, *Organizational Change Theories: A Synthesis* (Los Angeles, CA: SAGE Publications, 2008), p. 43.

⁴⁶² Bernard Burnes, *Managing Change: A Strategic Approach to Organisational Dynamics*, 5th ed (Harlow: Prentice Hall/Financial Times, 2009), p. 410.

⁴⁶³ Burnes, pp. 411–12.

⁴⁶⁴ Ibid.

process. The second section will explore the steps of a possible change process that could be followed.

1. Leadership and Change

Robert Quinn makes a useful distinction between incremental change and deep change that is quite instructive. 'Deep change differs from incremental change in that it requires new ways of thinking and behaving. It is change that is major in scope, discontinuous with the past and generally irreversible.'⁴⁶⁵ One of the premises behind this research thesis is that a deep change is needed if the SDA church is to become a place of liberation for people with disabilities. A brief review of the recent history of disability ministries in the SDA church will provide a reason for this premise.

Before 2011 the provision of ministries that raised awareness and promoted the inclusion of people with disabilities within the SDA church was mainly the result of private initiatives, such as ASNA in the UK.⁴⁶⁶ In 2011 the General Conference⁴⁶⁷ set up a committee to more specifically address the needs of people with disabilities.⁴⁶⁸ The Special Needs Committee, as it was known, was placed within the Sabbath School and Personal Ministries department. This was already quite a large department in the existing church structure, resulting in very little attention being given to the needs of people with disabilities.

However, in September 2015 the Administrative Committee of the General Conference voted to move the organisation of Special Needs Ministries directly under presidential oversight, thus the SDA church now has an assistant to the president for Special Needs Ministries. As a consequence, not only has this prompted the election of Special Needs Ministries coordinators all throughout the administrative structure of the Adventist church,

⁴⁶⁵ Robert E. Quinn, *Deep Change: Discovering the Leader Within*, Jossey-Bass Business & Management Series (San Francisco, CA: Jossey-Bass Publishers, 1996), p. 3.

⁴⁶⁶ Adventist Special Needs Association.

⁴⁶⁷ The administrative body of the Adventist world church.

⁴⁶⁸ See <http://www.adventistreview.org/church-news/story3520-why-adventist-church-is-placing-new-emphasis-on-special-needs>.

but it has also opened the possibility for placing a new emphasis on how fulfilling the church's mission can be an inclusive experience for people with disabilities.⁴⁶⁹

Thus far it can be said that there have been small incremental changes to the way in which the SDA church caters for people with disabilities. For example, the role of Special Needs coordinator is now an accepted leadership position in the church structure, and there is a Special Needs emphasis day on the yearly calendar of events. However, the experiences of the research participants, as explained above, seem to suggest that a deeper change is necessary if local SDA churches are to authentically be places of liberation.

In more recent times the idea of servant-leadership has become one of the most popular guiding metaphors for leadership and change, both in the Christian church and the business world.⁴⁷⁰ The term 'servant-leader' was first mentioned by Robert K. Greenleaf (1904-1990) in 1970 in an essay entitled 'The Servant as Leader'.⁴⁷¹ His main insight was that 'the great leader is seen as servant first'.⁴⁷² In other words, service is the most important dimension of life and leadership is one particular way in which service is rendered.⁴⁷³ In this way Greenleaf uses a Christian model to relate to the business world.

Theologically speaking, Osmer makes the point that by connecting the suffering servant of Isaiah with Jesus, New Testament writers like Paul present a servant-leadership model for the church. This model is characterised by power that seeks to create mutually caring relationships, as opposed to the use of power to dominate others.⁴⁷⁴ However, the idea of servant-leadership can easily be misunderstood. Some caution that servant-leadership should not be construed to mean that a person is compelled to meet the demands of those they serve.⁴⁷⁵ Instead, like Jesus, leaders will be more concerned about following what they

⁴⁶⁹ The Special Needs Ministries department includes work with the deaf, the blind, those with physical, mental health and emotional wellness challenges and their carers, as well as orphans. See <https://specialneeds.adventist.org>.

⁴⁷⁰ *Focus on Leadership: Servant-Leadership for the Twenty-First Century*, ed. by Larry C. Spears and Michele Lawrence (New York: J. Wiley & Sons, 2002).

⁴⁷¹ Spears and Lawrence, p. 3.

⁴⁷² Robert K. Greenleaf, *Servant Leadership: A Journey into the Nature of Legitimate Power and Greatness* (New York: Paulist Press, 1991), p. 7.

⁴⁷³ Greenleaf, p. 13.

⁴⁷⁴ Osmer, pp. 189–92.

⁴⁷⁵ Eddie Gibbs, *Leadership next: Changing Leaders in a Changing Culture* (Leicester: Inter-Varsity Press, 2005), pp. 23–24.

see God requiring of them with patience and determination. In fact, Spears offers ten helpful characteristics of the servant-leader gleaned from the writings of Greenleaf that serve to correct any misconceptions.⁴⁷⁶ These are: listening, empathy, healing, awareness, persuasion, conceptualisation, foresight, stewardship, commitment to the growth of people and building community.

Therefore, accepting the idea of servant-leadership as the ideal model for the church will cause us naturally to focus on concepts that describe organisational change in terms of ongoing processes rather than abrupt revolutionary transformation. This will also see the leader as any person that aspires to influence and change the behaviour of people around him or her, rather than being a domineering manager using a top-down style of leadership.

One of the assumptions behind the idea of deep change is that it is a process that needs to happen in an individual before it takes place in an organisation.⁴⁷⁷ This is not just a top-down process but can also be a bottom-up progression, thus underlining the significance of any person who is willing to champion the cause of people with disabilities. Quinn goes on to list three different paradigms that determine the way in which leaders conceptualise organisation and change.⁴⁷⁸ We will explore them separately.

1.1 Technical competence

The first worldview is called the technical competence paradigm.⁴⁷⁹ As the name suggests, it is built on professional training and competence in performing the technical tasks of the organisation. In other words, the organisation is viewed as a technical system. The level of competence that a person is able to demonstrate becomes the source of their power and credibility. This paradigm is built on the premise of personal survival and tends to have a more cynical attitude towards authority. Communication patterns usually follow a factual manner with a rational confrontational attitude towards those in authority.

⁴⁷⁶ Spears and Lawrence, pp. 5–8.

⁴⁷⁷ Quinn, p. 9.

⁴⁷⁸ Quinn, p. 122.

⁴⁷⁹ Quinn, p. 110.

At the local church level, technical competence is expected of pastors and is often measured in their yearly performance assessments.⁴⁸⁰ They are expected to perform competently such tasks as preaching, teaching, providing pastoral care and counselling, conducting ordinances like funerals and weddings, organising and conducting evangelistic outreach programs, chairing meetings and sending monthly reports to their administrators. One of the challenges with this paradigm is that the list of tasks is a very long one, so each new emphasis or initiative from top leadership is viewed as yet another additional task to be added to an already unassailable inventory.⁴⁸¹

Studies on the growing numbers of clergy suffering from symptoms of burnout⁴⁸² seem to suggest that a feeling of being overwhelmed by ever increasing tasks is a contributing factor.⁴⁸³ This being the case, it will be important to bear in mind that the recent emphasis on disability ministry from the General Conference can easily be interpreted as an added burden by pastors in the local church. To avoid this, it will be more prudent to focus on the Special Needs coordinator as the agent of change while acknowledging the significance of having the pastor on board as an important member of the guiding coalition.⁴⁸⁴

The coordinator will of course need to receive training to develop the technical understanding and skills needed to perform the duties associated with the role.⁴⁸⁵ At the same time it will be important to acknowledge that a person with a medical model view of disability will naturally tend to gravitate towards task competency as their understanding of organisation and change. While task competence is an important aspect of leadership, it must not be the guiding paradigm for the leader if deep change is the desired outcome.

⁴⁸⁰ Even though encouraged this is far from being a universal practice in the Adventist church. For an example of the discussion of formal pastoral assessment as a relatively recent phenomenon in the SDA church see, Leslie Pollard and Prudence Pollard, 'Ministerial Evaluation: Pitfalls and Opportunities', *Ministry*, 69.8 (1996), 5–8.

⁴⁸¹ Daniel Spaite and Debbie Salter Goodwin, *Time Bomb in the Church: Defusing Pastoral Burnout* (Kansas City, Mo: Beacon Hill Press, 1999), p. 71.

⁴⁸² See for example, Roy M Oswald, *Clergy Self-Care: Finding a Balance for Effective Ministry* (New York: The Alban Institute, 1991), p. 74; Cousins, pp. 53–55.

⁴⁸³ See for example, J. Fred Lehr, *Clergy Burnout: Recovering from the 70-Hour Work Week-- and Other Self-Defeating Practices*, Prisms (Minneapolis: Fortress Press, 2006). Here the author suggests that co-dependency is a contributing factor in clergy burnout.

⁴⁸⁴ John P. Kotter, *Leading Change* (Boston, MA: Harvard Business Review Press, 2012), pp. 53–68.

⁴⁸⁵ Currently the role description is quite limited and merely deals with questions of accessibility, solving transportation problems and recommendations for church involvement. See, General Conference of Seventh-Day Adventists, p. 102.

1.2 Political transaction

The second paradigm from which leaders conceive organisation and change is known as the political transactional.⁴⁸⁶ Here again personal survival is the underlying premise, but in this case the organisation is seen not just as a technical system but more in terms of a political organism. Thus, power comes from effectively negotiating transactions because the organisation is conceived as a system where resources are constantly being exchanged between individuals or groups of people. Communication is more conceptual and strategic, and the attitude towards authority tends to be very responsive, with a great willingness to compromise in order to resolve controversial issues.

At the local church level the pastor often has to facilitate transactions between various departmental leaders for human and financial resources as well as time. Adding the position of Special Needs coordinator can be viewed as complexifying the political landscape by adding another competing agenda for a congregation's limited resources. In a positive sense the pluralist attitude that comes from this political approach can be seen as a progressive indicator of a developing diversity that is now present in most Adventist churches.

On the other hand, a political transactional understanding of organisation can be a somewhat limiting paradigm from which to bring about change. This would be the challenge of having a coordinator who views disability primarily from a social model. Their tendency would be to focus on fighting for rights and equality rather than a transformation of values and attitudes. Deep change is not about competing for more money or sympathisers but rather about changes in beliefs, values and norms.⁴⁸⁷ Thus, the Special Needs coordinator will need to understand that while they will sometimes need to play a political transactional role, this is not their ultimate goal.

⁴⁸⁶ Quinn, pp. 111, 124.

⁴⁸⁷ Quinn, pp. 83–86.

1.3 The transformational paradigm

The third mindset is called the transformational paradigm.⁴⁸⁸ Here the underlying premise is the realisation of vision rather than self-interest. The organisation is seen as a moral system in which values and principles are of greater currency than political interests. The leader's power comes from their integrity in living according to the vision and values that are espoused. They have a more complex understanding of the organisation's systems so conflicts are resolved in a more complex and often risk-filled manner. Communication is more symbolic in nature, using powerfully clear mental images rather than specific directives for followers. From these descriptions, the transformational paradigm seems most fitting for the local church.

According to Quinn the transformational is the rarest paradigm but the only one that can bring about deep change in an organisation.

To internalize the transformational paradigm, the leader must become free of the organization's most powerful expectations, see it from a self-authorized perspective, and still care enough to be willing to be punished for doing whatever it takes to save the organization. Such processes are rare.⁴⁸⁹

Hence the power of the transformational leader seems to be their inspirational influence.

'The most potent lever for change is modelling the change process for other individuals.'⁴⁹⁰

Thus, in order for deep change to occur in Adventist churches in regard to ministry for and with people with disabilities, they will need Special Needs coordinators who have personally embarked on a type of 'hero's journey'.⁴⁹¹ That is, persons who have undergone deep change themselves and who understand the church organisation first and foremost in terms of its moral values, identity and culture, while also understanding the need for technical competence and political transactions.

⁴⁸⁸ Quinn, pp. 124–28.

⁴⁸⁹ Quinn, p. 127.

⁴⁹⁰ Quinn, p. 148.

⁴⁹¹ Quinn, p. 43.

Consequently, the choice of Special Needs coordinator will be of critical importance in leading the desired change. In the SDA church the act of choosing ministry leaders is usually done by the work of a nominating committee.⁴⁹²

The first obvious choice would be a person with some form of disability. They would have first-hand knowledge of the issues and challenges that are relevant to people with disabilities in the church, so the genuineness of their voice could not be questioned. However, as my son often reminds me, some people with disabilities do not necessarily want to be typecast as disability champions or leaders of disability ministries because they feel it makes it easier for their voice as an individual to be ignored, especially in environments where disability is viewed negatively and patronisingly. In other words, it should not be assumed that a person with a disability will automatically be the best candidate for Special Needs coordinator. Great sensitivity is needed.

Experience so far has shown that the Special Needs coordinator tends to be a carer or relative of a person with disabilities.⁴⁹³ There are both advantages and disadvantages to this that can be highlighted briefly.

From personal experience, I would say that being related to a person with disabilities usually demands some form of grappling with existential questions about disability and faith. This eventually necessitates the realignment of a person's values which is a key component of deep change.⁴⁹⁴ Personal connection also ensures a more intimate understanding and appreciation of the challenges people with disabilities face in the church. Thus, there is a strong internal motivation in advocating for change.

However, one of the disadvantages of being related is that the advocate can be seen as merely promoting a self-interest and thus be more easily ignored or dismissed. Having someone completely unrelated who has undergone a deep change in relation to disability can therefore be quite advantageous. The power of such an example can be greater than that of a person with a perceived vested interest, in that it exemplifies the kind of attitude

⁴⁹² The process of elections with specific descriptions of the work of the nominating committee is found in, General Conference of Seventh-Day Adventists, pp. 110–13.

⁴⁹³ This is based on attendance at ASNA training events for Special Needs coordinators where the majority identify themselves as relatives of people with disabilities.

⁴⁹⁴ Quinn, p. 46.

that is possible for the majority of church members who most likely will not be related to a person with a disability.

Whoever is chosen, as a catalyst for change, the Special Needs coordinator ought to be someone who embodies the change they would like to see in the local congregation.

Bearing this in mind, the next section will explore a possible process for leading change.

2. Organisational Change

Organisational change theory typically states that the nature of organisational systems is to normalise procedures.⁴⁹⁵ In this way the structures and processes of organisations encourage the maintenance of the status quo rather than the fostering of change.⁴⁹⁶ Using a systems perspective, Quinn describes a 'Transformational Cycle' with four phases which describes the dynamic evolutionary process that organisations go through.⁴⁹⁷ The cycle begins with an initiation phase, then progresses through uncertainty to transformation and ending with routinization. At each phase there are traps that can derail the cycle. These are illusion, panic, exhaustion and stagnation. Quinn concludes that organisational health comes from continuously cycling through the stages, giving times of both equilibrium and change.⁴⁹⁸ While this model gives a possible explanation of the dynamics behind transformational change, it does not give details of how to lead the change. For this we will turn to the insights of John Kotter.

Kotter suggests an eight-stage process of change which he lists as the following: establishing a sense of urgency, creating the guiding coalition, developing a vision and strategy, communicating the change vision, empowering employees for broad-based action, generating short-term wins, consolidating gains and producing more change, anchoring new approaches in the culture.⁴⁹⁹ These can be grouped in a threefold manner that would equate to Kurt Lewin's well-known three-step model of change: unfreezing, moving,

⁴⁹⁵ Demers, p. 2.

⁴⁹⁶ Quinn, p. 133.

⁴⁹⁷ Quinn, pp. 167–69.

⁴⁹⁸ Quinn, p. 167.

⁴⁹⁹ Kotter, p. 23.

refreezing.⁵⁰⁰ Kotter's first four stages are more foundational steps that are needed to address issues of inertia. The next three stages introduce new practices, and the final stage is about ensuring that lasting change is permanently embedded in the culture.⁵⁰¹ Hence Kotter's assertion is that while a person can operate within several phases at the same time, it is important not to skip a step but to work through the stages as they are enumerated in order to build the needed momentum to overcome the enormous forces of inertia.⁵⁰²

Kotter's insights are very valuable because he takes seriously the challenge of overcoming complacency and the forces that promote an unwillingness to change. These forces need to be faced if real deep change is to be achieved, especially as it is generally accepted that complacency is one of the reasons why most change efforts end in failure.⁵⁰³ We shall therefore go on to review Kotter's eight stages as a process for leading change in the church.

2.1 Establishing a sense of urgency

This first step is needed in order to gain people's cooperation. Kotter explains that when complacency is high, few people are interested in the issue around which change is needed. In fact he goes to great lengths to explain how debilitating complacency can be to all change efforts, giving nine sources of complacency which include the absence of a major visible crisis and the human tendency to deny new problematic information especially when people are already busy or stressed.⁵⁰⁴

The Special Needs coordinator will need to be aware that they are fighting against strong forces of complacency. For example, in most people's minds an emphasis on disability is optional because it does not represent any major visible crisis. Also, with so many other church ministries vying for attention there will be a tendency to dismiss any new information that may be presented.

⁵⁰⁰ Burnes, pp. 338–39.

⁵⁰¹ Kotter, p. 24.

⁵⁰² Kotter, p. 26.

⁵⁰³ Burnes, p. 447.

⁵⁰⁴ Kotter, pp. 41–44.

Some of the ways in which the urgency level can be raised could include the following: raising the issue of non-compliance with current legislation in regard to accessibility;⁵⁰⁵ using the testimonies of some of the participants in this research thesis to describe the general experience of people with physical disabilities in the SDA church here in the UK; arranging interviews with people with disabilities to give a first-hand testimony, especially if there are no people with disabilities in the church; presenting the latest statistics of the numbers of people with disabilities in society contrasted with how few there are in SDA churches in order to depict this an unreached people group; contrasting the narrow measures of success (baptisms and financial giving) with the way in which God seems to measure success, which includes creating a place of welcome for the marginalised; using all available opportunities to engage the church in dialogue about its values and principles.⁵⁰⁶

In other words, the Special Needs coordinator needs to use the opportunities at their disposal to bring about a sense in the congregation that something fundamental needs to change in relation to how people with disabilities are viewed and treated. This is a tall order for one individual to deliver, hence the need for the next step.

2.2 Creating a guiding coalition

Since major change is so difficult to achieve, Kotter asserts that neither a lone strong-willed charismatic leader nor a low-credibility committee are enough to bring it about.⁵⁰⁷ The main reason for this is the rapid pace of change in the business environment. Even though the church does not operate in a fast-paced business environment, it does exist in a social environment that is rapidly changing, especially in terms of technology and social media. These influences are so powerful today that it does not need much imagination to think of the damage that one negative report on social and local media could do to tarnish the credibility and witness of a local congregation.

⁵⁰⁵ Unfortunately, some church buildings are still not wheelchair accessible as stipulated in the Equality Act 2010.

⁵⁰⁶ Adventists usually engage in weekly, monthly and quarterly times of dialogue. Weekly dialogue takes place during the hour allotted to Sabbath School discussion, monthly discussions take place during church leadership meetings (also known as church board meetings), quarterly (once every three months) discussions happen during constituency meetings which are known as business meetings.

⁵⁰⁷ Kotter, pp. 53–57.

As with other Christian denominations, change takes place very slowly in the SDA church. Kotter admits that in a slower moving, less globalised environment there does not need to be as much effort put into creating a guiding coalition.⁵⁰⁸ Nevertheless, given how difficult it can be to bring about change and how easy it can be to end up frustrated and disillusioned, it would be wise for the Special Needs coordinator to create a guiding coalition.

The creation of committees is a well-established tradition within the SDA church, so the formation of a Special Needs committee would not be out of character. This team should include key influential people such as the pastor, one of the local church leaders such as an elder or a member of the diaconate team and, if possible, a person with a disability. Kotter suggests that the two key characteristics for the success of the group are creating trust and developing a common goal.⁵⁰⁹ When it comes to creating trust, the coordinator will be endeavouring to facilitate a deep change experience for the members of the committee. Having a shared story of change in attitude towards the subject of disability can prove to be a powerful bond. It would be difficult to put a time limit on this, but creating trust within the team is an important first step in achieving the ultimate goal, which is to lead a deep change process in the congregation as a whole. Painting a clear and compelling picture of the future will be an integral part of this and is therefore addressed in the next step.

2.3 Developing a vision and strategy

This third stage reflects the fact that all scholarship on leadership eventually addresses the importance of having a guiding vision. Definitions may vary but the common denominator seems to be a picturing of a desired future. Kotter, for example, defines vision as, ‘a picture of the future with some implicit or explicit commentary on why people should strive to create that future’.⁵¹⁰ Consequently, the three purposes of a good vision are to clarify the general direction, to motivate action and to coordinate actions.⁵¹¹

⁵⁰⁸ Kotter, p. 68.

⁵⁰⁹ Kotter, p. 68.

⁵¹⁰ Kotter, p. 71.

⁵¹¹ Kotter, pp. 71–73.

Collins and Porras point out that 'A well-conceived vision consists of two major components: core ideology and envisioned future.'⁵¹² The ideology describes the character and identity of an organisation and is that which is unchanging. This is expressed in the core values that it holds,⁵¹³ and the core purpose for which it exists.⁵¹⁴ We will briefly consider the two elements of the ideology and then the envisioned future.

The core purpose of an organisation parallels what some authors seem to refer to as the mission of the group.⁵¹⁵ Hence Gibbs, for example, makes the observation that in a church context the mission will usually be connected in some way to the Great Commission of Jesus as recorded in Matthew 28:18-20.⁵¹⁶ In other words, it would be expected that a church purpose or mission statement will mention some form of disciple making and preaching the Gospel.

By way of illustration, the official mission statement of the SDA church as voted on 13 October 2014 reads as follows, 'The mission of the Seventh-day Adventist Church is to call all people to become disciples of Jesus Christ, to proclaim the everlasting gospel embraced by the three angels' messages (Revelation 14:6-12), and to prepare the world for Christ's soon return.'⁵¹⁷ There are a growing number of local SDA churches that have clearly articulated mission statements, as evidenced by reading their weekly bulletins or visiting their websites. Therefore, it can be said that mission consciousness should be quite high in Adventist churches, at least theoretically. In other words, the purpose element to SDA ideology should be quite strong.

When it comes to the values element of an ideology this seems to be generally underdeveloped in the Christian context. In fact, just twenty years ago Aubrey Malphurs observed that generally in the Christian world there were few pastors or churches that had

⁵¹² *Harvard Business Review on Change*, Harvard Business Review Paperback Series (Boston, MA: Harvard Business School Press, 1998), p. 23.

⁵¹³ *Harvard Business Review on Change*, pp. 26–29.

⁵¹⁴ *Harvard Business Review on Change*, pp. 30–35.

⁵¹⁵ Gibbs, p. 132.

⁵¹⁶ Gibbs, pp. 61–78.

⁵¹⁷ <http://www.adventist.org/en/information/official-statements/statements/article/go/-/mission-statement-of-the-seventh-day-adventist-church/> (Accessed 18 June 2017).

taken the time to articulate their values.⁵¹⁸ Given the emphasis this has received since then, one would expect that the picture today is quite different. Yet it is quite instructive to note, from the examples that one Adventist author cites in his recent book, that the SDA church generally still seems to be lacking in the area of being values-led.⁵¹⁹ This, however, does not mean there are no values formulated by the Adventist church.

On 10 October 2004 three value statements were officially articulated by the General Conference. The second reads,

Our sense of mission is driven by the realization that every person, regardless of circumstances, is of infinite value to God and thus deserving of respect and dignity. Through God's grace every person is gifted for and needed in the diverse activities of the church family.⁵²⁰

This makes an important link between mission and values, illustrating Collins and Porras' ideological component of vision, and at the same time it provides a good grounding for an emphasis on a disability ministry.

However, this also illustrates the relationship between conscious and unconscious values as well as the tension between personal versus organisational values.⁵²¹ Not only do values need to be held at a conscious level in order for them to be effective in the change process, organisational values also need to be translated into individual values if they are to affect actual behaviour rather than merely remain as aspirational. The above statement currently functions as merely an aspirational value of the organisation rather than an actual personal value for members in local churches. Nevertheless, this could provide the Special Needs coordinator with a starting point from which to help a congregation to articulate its core values to include the esteem it has for people with disabilities in its midst. In this way, the coordinator will be seeking to facilitate deep change in the ideology that fuels a congregation.

⁵¹⁸ Aubrey Malphurs, *Values-Driven Leadership: Discovering and Developing Your Core Values for Ministry* (Grand Rapids, MI: Baker Books, 1996), p. 9.

⁵¹⁹ Llewellyn Edwards, *Values-Led Lives*. (Grantham: Stanborough Press, 2017).

⁵²⁰ <http://www.adventist.org/en/information/official-statements/statements/article/go/-/values/> (Accessed 18 June 2017).

⁵²¹ Malphurs, *Values-Driven Leadership*, pp. 48–51.

With regard to the envisioned future component of Collins and Porras' articulation of vision, Quinn brings out the importance of finding a vision from within, both of the organisation and of individuals.⁵²² Listening to the voice of people with disabilities first is possibly one of the most important tasks to perform in endeavouring to formulate an envisioned future. The findings articulated in the descriptive-empirical task of chapter 5 above can aid in presenting that inner voice if there are no people with disabilities immediately available in a congregation. Part of this envisioned future, as highlighted in the previous chapter, will be to see the flourishing of authentic friendships between all people regardless of their abilities. So, with an understanding of the mission and values behind its ideology and an envisioned future of inclusive positive regard for people with disabilities, the vision of being a liberating community can be realised.

The idea of strategy is to show the initial details of how the vision will be accomplished.⁵²³ Thus the Special Needs committee will need to work out the steps that it intends to follow in order to realise the envisioned future. It is hoped that some of the steps mentioned in this chapter would form a natural part of such a strategy.

2.4 Communicating the change vision

Failure to communicate the vision well is said to be one of the key reasons why transformations fail,⁵²⁴ hence the importance of this fourth step. While acknowledging that communication theory is very complex and highly developed, we can accept that basic communication models describe the significance of a number of key elements in the communication process which are: the sender, the medium, the message, the receiver, the effects and feedback.⁵²⁵ We will briefly focus on the three basic areas suggested by Malphurs as being vital to the process of vision communication which are, sender, message and receiver.⁵²⁶

⁵²² Quinn, p. 203.

⁵²³ Kotter, p. 78.

⁵²⁴ Kotter, p. 87.

⁵²⁵ Swen Windahl, Benno Signitzer, and Jean T. Olson, *Using Communication Theory: An Introduction to Planned Communication* (London: Sage Publications, 1992), pp. 8–17.

⁵²⁶ Malphurs, *Values-Driven Leadership*, p. 100.

The sender is the one who has the main responsibility to ensure that the core values and vision are sent. In the SDA church context, the pastor is generally regarded as the 'point person' or spokesperson for the congregation.⁵²⁷ Without the support of the pastor it is highly unlikely that any changes in vision or values will occur. However, the suggestion in this thesis is that the key driver for this process is the Special Needs coordinator together with a strong guiding coalition that includes the pastor. One of the most significant contributions in communicating the vision of change will be the example of these members. Being able to 'walk the talk' is one of the most powerful ways of communicating a new direction.⁵²⁸

The message that is to be communicated needs to have several characteristics. Firstly, it should be as simple and clear as possible.⁵²⁹ This will mean that it is to be jargon- and cliché-free as well as avoiding being too convoluted or over complicated. This is especially ideal for inclusion on printed bulletins. Secondly, it should use metaphors and examples that can communicate ideas effectively.⁵³⁰ In a church context the natural place to look for word pictures and analogies will be the Bible. The pastor in particular will have a great opportunity to use powerful Biblical metaphors to explain and unpack the ideas in the vision during the sermon. Thirdly, the message will need constant repetition.⁵³¹ All available opportunities, whether great or small, will need to be utilised in order to ensure that the vision is effectively communicated.

The receiver is significant because they are the majority through whom the values will be lived and therefore experienced by people with disabilities. The acceptance of a vision that requires change is challenging both intellectually and emotionally which explains why it is so difficult to bring about. This will mean that communicating the vision and values needs to take place in multiple forums,⁵³² through both formal and informal conversations,⁵³³ which in

⁵²⁷ Malphurs, *Values-Driven Leadership*, p. 101.

⁵²⁸ Kotter, pp. 97–99.

⁵²⁹ Kotter, pp. 91–93.

⁵³⁰ Kotter, pp. 93–95.

⁵³¹ Kotter, pp. 96–97.

⁵³² Kotter, pp. 95–96.

⁵³³ Malphurs, *Values-Driven Leadership*, p. 112.

turn will open for two-way communication.⁵³⁴ This reciprocal process will be very beneficial in allowing questions to be addressed as well as fostering a wider ownership of the change.

In the SDA church context, the ideal way in which communication will develop will be according to the following general procedure. The new message is formulated in the sub-committee, which in this case is the Special Needs committee, then it is taken to the board of elders as an initial clarity check before being presented to the church board, which is the chief governing committee of the church.⁵³⁵ Once it is ratified in the church board it can either be discussed at a church business meeting or be directly introduced to the church at large at a worship service. Even though this seems to be a long and slow process, it is important to follow this course if the ultimate goal is to bring about a deep change in the congregation.

2.5 Empowering volunteers for broad-based action

Here we have replaced the term ‘employee’ with ‘volunteers’ since they are the main constituents in the local church. This of course is one of the key differences between churches and businesses, giving rise to discussions of issues of motivation and accountability.⁵³⁶ The central notion behind the idea of empowerment is the removal of obstacles that may hamper people’s actions. Kotter mentions several obstacles, three of which we will address here.

Firstly, there may be structural barriers that make it difficult to act.⁵³⁷ The most obvious barriers are physical ones, so the Special Needs coordinator will need to help the church become compliant with current legislation by removing any physical access barriers. Another way in which the organisational structure may hamper action is the promotion of a silo mentality, where each department functions independently of the others and is primarily concerned with its own performance. This is a potential danger in the Adventist context especially with the plethora of ministries that are possible in a church. Limited resources can then lead to a more competitive rather than cooperative spirit. In this

⁵³⁴ Kotter, pp. 101–3.

⁵³⁵ General Conference of Seventh-Day Adventists, p. 129.

⁵³⁶ Cousins, pp. 123–47.

⁵³⁷ Kotter, p. 106.

situation, it may be best for the Special Needs coordinator to present their emphasis in terms of helping each existing department to work out how the new values will be adapted to their ministry. Since deep change is the ultimate goal, the first role will be to help departmental leaders think positively about being inclusive of people with disabilities.

Lack of training is the second barrier for members.⁵³⁸ Training is needed to address the skills, behaviour and attitudes that will be needed for the change. Fortunately, there is a growing consciousness about disability awareness in the SDA church, with special emphasis days being an integral part of the yearly church calendar and training events being organised at every level of the organisation. However, here again the Special Needs coordinator will need to think in terms of ongoing training rather than settling for a few events taking place each year. One cannot expect people to change habits and attitudes that have been built up over many years by merely giving them three or four days of education per year.⁵³⁹ In this regard the idea of organisational learning and unlearning may be useful.

According to Tsang and Zahra, 'Organizational unlearning refers to the discarding of old routines to make way for new ones, if any.'⁵⁴⁰ According to their definition, unlearning is an intentional act and it combines both behavioural and cognitive features. They make the point that both learning and unlearning are varieties of organisational change,⁵⁴¹ and that individual unlearning presents a significant barrier to organisational learning.⁵⁴² Hence there is a need for Special Needs coordinators to have in mind a process of training that will help individuals unlearn any ableist practices before attempting to have them instil new values and routines.

The third barrier to empowerment are troublesome leaders.⁵⁴³ These can be individuals with vested interests who fear that change will bring a loss of power and position,⁵⁴⁴ or who have deeply ingrained ideas from years of practicing the same habits that make them

⁵³⁸ Kotter, p. 110.

⁵³⁹ Kotter, p. 112.

⁵⁴⁰ E. W.K. Tsang and S. A. Zahra, 'Organizational Unlearning', *Human Relations*, 61.10 (2008), 1435–62 (p. 1437) <<https://doi.org/10.1177/0018726708095710>>.

⁵⁴¹ Tsang and Zahra, p. 1446.

⁵⁴² Tsang and Zahra, p. 1451.

⁵⁴³ Kotter, p. 116.

⁵⁴⁴ Malphurs, *Values-Driven Leadership*, p. 129.

resistant to new ideas.⁵⁴⁵ Whatever the reason, these people can hamper the adoption of new values by volunteers because of their words and actions. Kotter points out that the best way to deal with this type of problem is honest and direct dialogue.⁵⁴⁶ In a church setting this will need to be done by the pastor who can engage the person in such a way as to ascertain what the hindrances are and how they can be collaboratively overcome.

2.6 Generating short-term wins

This sixth stage acknowledges that since the type of change that is being described demands a slow process, the danger of losing momentum will be very real. To address this, it will be important to present evidence that the changes are being beneficial. Kotter mentions six ways that noticeable improvements help to facilitate transformations.⁵⁴⁷ Firstly, they provide evidence that the sacrifices being made are worthwhile. Secondly, they give an opportunity to give positive feedback which in turn builds morale and increased motivation. Thirdly, they supply the guiding coalition with the data they need to continue to fine-tune the vision and strategies. Fourthly, they present undisputable evidence that can help silence some of the arguments of cynics and change resisters. Fifthly, they encourage all leaders to stay with the change process. Finally, they help in the building of momentum especially in enlisting the support of those who have been sitting on the fence.

In the church context, short-term wins will most likely take the form of feedback from people with disabilities who are benefiting from the changes. These can include, for example, comments on websites about the provision of subtitles for those who may be deaf, the completion of small physical structural changes within an allotted deadline, or the word of thanks from someone with a disability being included in leading or taking part in a service perhaps for the first time. This naturally infers that the Special Needs committee will be constantly monitoring progress and looking for avenues through which changes and improvements can be highlighted.

⁵⁴⁵ Kotter, p. 117.

⁵⁴⁶ Kotter, p. 118.

⁵⁴⁷ Kotter, p. 127.

2.7 Consolidating gains and producing more change

The underlying thought behind this seventh stage is to ensure that the change process does not come to a standstill. The danger of celebrating short-term wins is that people can easily be lulled back into a sense of self-congratulatory satisfaction, eventually leading to the debilitating complacency that so easily thwarts the change process. Even though this is a valuable insight, the scenarios that Kotter uses to describe this stage of the process only seem fitting in a business rather than church context.

The idea behind consolidating gains and pushing for more change is prompted by the turbulent environment created by a rapidly changing business world and the way in which organisations are made up of interconnected parts.⁵⁴⁸ As such this stage would be more fitting in the upper right-hand side of the framework of change highlighted above, where large-scale, organisation-wide rapid changes are needed. This is diametrically opposite to the personal and group change being proposed in this thesis. Hence it would be more fitting to think of strategies for keeping the change going as naturally belonging to the previous step of generating short-term wins. Together these two steps could be renamed under the heading 'sustaining momentum'.

In addressing the topic of sustaining momentum, Burnes points out the importance of giving support to the change agents and reinforcing desired behaviour.⁵⁴⁹ Support for the team that is leading the change is important because the difficulties inherent in the change process can easily lead to demoralisation. Although financial rewards are often used in the business world to offer encouragement, in the church setting the use of verbal incentives should not be underestimated. As shown by the work of Chester Barnard (1886-1961) and Abraham Maslow (1908-1970), praise, both private and public, is arguably an even more powerful tool for providing support.⁵⁵⁰ This is primarily because praise taps into a person's social and esteem needs. At the local church level this will most likely need to come from the pastor. However, support for Special Needs coordinators can also come from higher up

⁵⁴⁸ Kotter, p. 140.

⁵⁴⁹ Burnes, pp. 462–64.

⁵⁵⁰ Burnes, pp. 63–67.

in the church organisation, for example, in the form of a coaching relationship with the Conference Special Needs coordinator.

Reinforcing desired behaviour is important because people tend to do those things that have some type of reward connected to them.⁵⁵¹ This tendency can be used to emphasise the types of attitudes and behaviours that embody the desired change. Thus, the Special Needs coordinator will need to look for occasions to give special recognition to individuals who embody the new values that are being promoted, thereby reinforcing the type of behaviour that is being aimed at.

2.8 Anchoring new approaches in the culture

This final stage acknowledges that organisations are not value-free environments but that everything they do is governed by their culture. This being the case, it will be important to define what we mean by organisational culture.

One way of thinking about organisational culture is that proposed by Cummings and Worley, which is comprised of four constituent elements arranged at different levels of awareness, like the concentric rings of an onion.⁵⁵² At the deepest level (the core of the onion) are the 'basic assumptions' that function at an unconscious level and that dictate how problems should be solved, based on assumptions about human relationships and how to relate to the environment. The next layer of awareness includes 'values' which describe what ought to happen in the organisation. This helps members understand those things that are given most weight and attention. The third layer is comprised of 'norms' which provide guidance as to how members should behave in different situations. They are referred to as the unwritten rules of behaviour. The outer layer of cultural awareness is comprised of 'artefacts' which are the visible manifestations of the other levels. These include such things as the observable behaviours of members or the procedures and rules that are used.

Kotter defines culture as the 'norms of behavior and shared values among a group of people'.⁵⁵³ Thus his definition groups the four layers of the previous model into just two

⁵⁵¹ Burnes, p. 464.

⁵⁵² Thomas G. Cummings and Christopher G. Worley, *Organization Development and Change*, 7th ed (Cincinnati: South-Western College Pub, 2001), pp. 502–3.

⁵⁵³ Kotter, p. 156.

areas. Norms of behaviour refers to the common and persistent ways of acting among people in a group and that new members are rewarded for adopting. Shared values are the important concerns and goals that are shared by group members and that persist even with changes in group membership. Kotter admits that shared values are harder to change than behavioural norms because they are more invisible and deeply embedded in the culture. Also, because shared values are the result of many years of experience, he argues that cultural change has to come at the end of a transformational process and not at the beginning.⁵⁵⁴

Although both of these definitions seem to give a neat and tidy way of understanding culture, the reality is often quite different. This is why some would say that it is futile to attempt to define organisational culture.⁵⁵⁵ Within cultures there can be various subcultures, and then disagreements can lead to countercultures, so this is an area that is fraught with complexity. Nevertheless, the power of the guiding culture needs to be addressed if a deep change is to take place in an organisation.

Since new values take time to be rooted deeply into a culture, the longevity of the leader of change is of vital importance, otherwise when the leader is replaced the change initiative might collapse. Within the Adventist culture there are three dynamics that are pertinent here.

Firstly, although there are a few exceptions, pastors do not stay in one pastoral district for more than ten years.⁵⁵⁶ On average they are moved every 5-8 years. Hence any change initiatives associated with an individual pastor tend to die out once they have left. This is one reason why it is important to have someone other than the pastor leading the change.

⁵⁵⁴ Kotter, p. 164.

⁵⁵⁵ Burnes, p. 203.

⁵⁵⁶ The topic of length of tenure is an ongoing debate within the SDA church. Even though there has been a lengthening of average time spent in a pastoral district in the past twenty years, Adventist pastors would still be considered as having short-term pastorates. See for example, Arnold Kurtz, 'Short-Term Pastorates', *Ministry*, 53.1 (1980), 14–15; Erik C. Carter, 'Discovering Stability in the Pastorate', *Ministry*, 84.10 (2012), 13–15; Joseph Kidder, 'Should I Move? Nine Factors to Consider before Making the Change', *Ministry*, 88.1 (2016), 20–23.

The second dynamic is the term of office for ministry leaders in the church. The recommended length for a term of office is currently one or two years.⁵⁵⁷ Although re-election is possible and is often practiced, there is a potential danger that this high turnover rate can stall a change process, especially if the Special Needs coordinator is not allowed to continue.

A third dynamic worth considering is the influence of longstanding members, referred to by Malphurs as matriarchs or patriarchs.⁵⁵⁸ The respect that these people have in a congregation can decide the fate of any change process. In the same way, there are also many cases where elders have held a leadership position in a church for more than twenty years, particularly in smaller congregations. They often regard themselves as the cultural guardians of the church, resulting in all changes needing to gain their approval first. This will require political sensitivity on the part of the Special Needs coordinator in order to be dealt with satisfactorily.

Given the above considerations of culture in general and Adventist culture in particular, one of the most pertinent questions that can be asked is whether or not it can be changed. The literature dealing with culture change shows a huge variation in belief as to whether culture can consciously be successfully changed.⁵⁵⁹ Those on the optimistic end of the spectrum believe that culture can indeed be managed and changed by leadership. At the opposite end are those who point out that the many influences that converge to condition individual values and beliefs, puts culture change outside the reach of management.⁵⁶⁰

In line with Kotter's definition we can conclude that even though the values element of a church's culture is harder to change than its behavioural norms, a deep change in culture is possible. Switching to a more theological discourse, one of the main reasons for this optimistic view is the fact that the church, as an organisation, is built on the premise of deep change known as sanctification.⁵⁶¹ This is more than a one-time occurrence but rather a process of continual growth and change. As expressed in the words of Paul in 2 Corinthians

⁵⁵⁷ General Conference of Seventh-Day Adventists, p. 72.

⁵⁵⁸ Aubrey Malphurs, *Advanced Strategic Planning: A New Model for Church and Ministry Leaders*, 2nd ed (Grand Rapids, MI: Baker Books, 2005), p. 57.

⁵⁵⁹ Burnes, p. 210.

⁵⁶⁰ Burnes, p. 211.

⁵⁶¹ Malphurs, *Advanced Strategic Planning*, p. 80.

3:18, 'And we, who with unveiled faces all reflect the Lord's glory, are being transformed into his likeness with ever-increasing glory, which comes from the Lord, who is the Spirit.' In other words, continual transformation should be considered as part of the DNA of the Christian church, which will include both shared values and behavioural norms.

This stage shows the need for the guiding coalition to be conscious of the culture of the congregation all through the transformation process. The desired outcome is a cultural shift, a change in the way people with disabilities are regarded and treated in the church.

Conclusion

Thus, we can summarise this chapter on the pragmatic task. Based on the servant leadership example of Jesus, the Special Needs coordinator will be a change agent in the local church. Working from a transformational paradigm of organisation and change, the coordinator will be guided by the following seven step process in order to lead a deep change in their congregation:

1. Establishing a sense of urgency
2. Creating a Special Needs committee as a guiding coalition
3. Developing a vision and strategy
4. Communicating the change vision
5. Empowering volunteers for broad-based action
6. Sustaining momentum
7. Anchoring new approaches in the culture

Chapter 9 – Conclusion

This research based thesis, by centring the voices of people with disabilities, set out to explore how the SDA church, with its particular wholistic emphasis on health, could be a Christian denomination that is authentically liberating for people with disabilities. The underlying assumption was that a wholistic anthropology, when combined with an emphasis on individual responsibility for health, will lead to a form of health essentialism that discriminates against people with disabilities. The findings supported this assumption through the themes of insignificance, discrimination and stereotyping. However, were the church to expand its health emphasis beyond individual responsibility and towards communal responsibility, the cultural shift needed to create an inclusive environment for people with disabilities would become possible.

An interpretive exploration of the experiences of the research participants using the social sciences, was shown to give greater depth to an understanding of the attitudinal barriers that people with disabilities face in the church. Learning how people react to having their ableist assumptions challenged, and recognising the dynamics that trigger the reactions of fear, pity and disgust, led to a clearer understanding of the lived experience of disability in the SDA church. Such an interpretive investigation also demonstrates the way in which a facilitated dialogue can assess and analyse the themes of insignificance, discrimination and stereotyping in a local church context.

By bringing theological beliefs and ethical values face to face with disability as a normative response to the research, relationality was found to be the recurrent key. Thus, should the SDA church learn to speak of the image of God in relational terms, i.e. in terms of God's gift of his relationship to humankind that is independent of our ability to receive it, this would address the theme of insignificance shown to result from erroneous ideas about the agency of people with disabilities.

Exploring the concept of sin in terms of relationality showed that fear was, and still remains, the principal obstacle to overcome. Hence, the SDA church should learn to articulate its health message as primarily to restore relationship. This would underline the message that

all healing processes are illustrative of God's initiative in restoring a trust relationship with himself, thereby demonstrating the way in which the SDA church can connect its health message with an authentic liberationist position.

When viewed relationally, eschatology, which is central to Adventist thought, can positively address discriminatory ideas, such as people with disabilities being abnormal or less than ideal. This can particularly be achieved by exhibiting an attitude of greater humility when making assertions about our future.

In terms of ethics, were the SDA church to expand its individual health focus to incorporate church and community health, it would find itself more in correspondence with the wholeness models found in those biblical passages which speak of the full participation of people with disabilities in the community.

Listening to the collective voice of the research participants, I would summarise by saying that the common solution being called for was the fostering of genuine friendships between people with and without disabilities. The interviewees who recounted occurrences of discrimination and stereotyping were repeatedly calling for the development of a mindset that acknowledges the existence of disability but has positive regard for it. Those who described experiencing insignificance were asking for the nurturing of healing relationships, not as a one-way demonstration of power from the strong to the weak, but rather as a reciprocal experience given and received both by people with and without disabilities. The participants who described instances of insensitivity were calling for a transformation of core values that would see them appreciated as members equal with all others.

A pragmatic process for leading the kind of transformational change that the research participants were calling for was outlined. Steered by a group of people with disabilities at its core, the process outlines the steps needed to take a milieu characterised by insignificance, discrimination and stereotyping and gradually changing it into a liberating environment characterised by ministry inclusion, proactive adaptability, involvement space and belonging.

Thus, we can say that the SDA church will be regarded as a liberating social space for people with disabilities when it intentionally positions people with disabilities to lead it through all

the stages of the pastoral cycle. Firstly, when it gives space for people with disabilities to voice their experiences of the varying attitudes they face in church. Secondly, when it actively encourages an honest dialogue within its community that explores the reasons behind these attitudes. Thirdly, when it is willing to use a relational lens in exploring theological and ethical concepts and to expand its understanding of health to include communal responsibility. Finally, when it empowers people with disabilities to help it work through a process of deep change in all the structures of the organisation.

Therefore, the significance of this study is that it illustrates the impact a wholistic anthropology can have on disability by drawing on the SDA church as an example. When combined with an emphasis on individual responsibility for health, the SDA church illustrates how the ensuing health essentialism can manifest itself in negative experiences such as insignificance, stereotyping and discrimination. On the other hand, if a wholistic anthropology is combined with a communal health emphasis, it has the potential to create a more inclusive and liberating environment for people with disabilities.

This thesis was limited to the voice of people with physical disabilities and as such it has left many other questions unanswered. For example, what is the experience for those with less obvious disabilities, such as epilepsy, or those with learning difficulties? Another voice that would help to give greater richness to this process of disability enlightenment in the church would be that of the carers. Further still, the rich multi-cultural composition of the Adventist church can provide fertile material for research into the intersection of cultural expectations and biases on the experience of disability. It is hoped that this thesis will be a springboard for more extensive research that will result in ever widening change within the SDA church.

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Main title: A critical study of life as a Seventh-day Adventist adult from the perspective of physical disability

Interview questions

1. Personal data
 - ☐ Male or female?
 - ☐ Age
2. Personal experience
 - Can you tell me about your impairment?
 - ☐ Medical diagnosis?
 - ☐ Prognosis?
 - ☐ Describe a typical day in your life.
 - ☐ How do you experience your impairment in everyday living?
 - ☐ What kinds of things frustrate you?
 - ☐ What advantages/disadvantages do you experience as a result of your impairment?
3. Church experience
 - A. How long have you been attending your local congregation?
 - B. Describe a typical day at church.
 - C. What changes has your local congregation made in order to accommodate your needs?
 - D. Describe your experience of ministry involvement.
 - E. Describe your experience of participating in and leading worship.
 - F. Describe your experience of being prayed for.
4. General questions:
 - ☐ In what ways do you feel your disability impacts your life at church?
 - ☐ Do you feel you are an asset or liability to your church? Explain.
 - ☐ How do you experience being included in the life of your church?
 - ☐ What more could your local church do to make you feel fully included?
 - ☐ What gives you a feeling of exclusion?
5. If there was one thing you could say to your church family about how to treat you as a person with an obvious physical disability what would it be?
6. Is there anything else you would like to tell me before we end the interview?

Appendix B

CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.



Title of Study: A critical study of life as a Seventh-day Adventist adult from the perspective of physical disability.

King's College Research Ethics Committee Ref: KCL/14/15-86

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking/initialling each box I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes mean that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element I may be deemed ineligible for the study.

Please tick
or initial

☐

Please tick
or initial

1. I confirm that I have read and understood the information sheet dated 03/12/2014 version number 1 for the above study. I have had the opportunity to consider the information and asked questions which have been answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. Furthermore, I understand that I will be able to withdraw my data up to the time of submission of the research project. ☐
3. I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the UK Data Protection Act 1998. ☐
4. I understand that my information may be subject to review by responsible individuals from the College for monitoring and audit purposes. ☐
5. I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications. ☐
6. I agree to be contacted in the future by King's College London researchers who would like to invite me to participate in follow up studies to this project, or in future studies of a similar nature. ☐

7. I agree that the research team may use my data for future research and understand that any such use of identifiable data would be reviewed and approved by a research ethics committee. (In such cases, as with this project, data would not be identifiable in any report). ☐
8. I understand that the information I have provided will be submitted within a research project and I wish to receive a copy of it. ☐
9. I consent to my interview being audio/video recorded. ☐
10. I understand that I must not take part if I fall under the exclusion criteria as detailed in the information sheet and explained to me by the researcher. ☐

Name of Participant

Date

Signature